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ABSTRACT

This Federal Council on Aging report contains recommendations for a national policy regarding services for the frail elderly and describes the principles on which the recommendations are based. Recommended core services are discussed and characteristics and statistics relating to the frail elderly are identified. The report describes existing help, both in terms of family and social support. Government studies concerning care for the mentally and physically disabled, protective services, age discrimination, and care for veterans are cited. Policy recommendations from the private sector regarding long-term care for the elderly are also reviewed. References are provided along with two appendices containing the instrument used to obtain information for the report and hypotheses and questions used to complete the report. (JAC)

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ED216300

A Staff Report

DECEMBER, 1978

Public Policy and the Frail Elderly

Dorethea Lewis, Editor

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While the Council is grateful to many who contributed, special recognition is given to Leonard Cain, Professor of Sociology and Urban Studies, Portland State University, Portland, Oregon, and William G. Bell, Director, Multidisciplinary Center on Gerontology, Institute for Social Research, Florida State University, Tallahassee, Florida, who were able to take some time from their academic responsibilities to serve as consultants to the frail elderly project.

Some of the many academicians and practitioners in the field of gerontology and social policy development who shared their views and concerns with the author in the development of this study are identified in the reference section through citation of their relevant publications. Many of the ideas were drawn from personal contacts with these and other professionals and with lay persons -- of all ages. It would be difficult to list all names lest some be missed. It is impossible to express sufficient gratitude for the interest they evidenced in this study and in the frail elderly.

And finally, appreciation must be expressed to Ms. Karen A'Vant and Mrs. Gwendolyn Fortune of the FCA Secretariat for their patience and skill in typing the report and to Mrs. Dorethea Lewis for her skillful editing.

PREFACE

THIS STAFF REPORT covers recommendations for action, describes the principles on which the recommendations are based, and provides background on both the process of development within the Federal Council on the Aging and relevant recommendations and action by other government and non-government organizations.

It attempts to capture the observations and views of many organizations and individuals, academicians, practitioners, and citizens including the elderly. In some instances, the Council solicited these views. In a gratifying number of cases, however, individuals -- having heard of the Council's efforts -- were stimulated to contact members and staff to volunteer their own reactions and experiences.

Because future services to older people must be provided within the existing framework of services by addition or substitution -- all requiring change and adjustment -- the FCA has had to look most carefully at that existing framework, an often contradictory, overlapping, complex fiefdom of shredded and gapping services, group concerns, and action.

The Report records specific actions taken by the Council on issues considered by the members in official session. The rest of the material necessarily reflects the perspective of the author, Cleonice Tavani. She served as staff director of the Federal Council on the Aging since the Council's inception in 1973 to August, 1978.

FOREWARD

In its first Annual Report issued in 1975, the Council identified as a priority concern that group among the elderly -- usually the oldest of older Americans -- with an accumulation of health, social, economic and environmental problems which impede their independent living to the extent that they need continuing personal assistance.

During the past four years, (prior to this publication date),the first three under the leadership of Monsignor Charles Fahey, then Chairman of the Task Force on the Frail Elderly, and the past year under the direction of Fernando Torres-Gil, the Council developed a conceptual framework within which to make a determination of a national policy regarding services to the frail elderly. As noted in previous reports, the Council claims no special originality for the name. It was selected because of the need for a dramatic term to focus attention on this very special grouping of the elderly.

At the July 1978 Council meeting, the Special Aging Populations Committee, chaired by Mr. Torres-Gil, was given the responsibility of proposing recommendations for final disposition of the Frail Elderly Report. The Committee, thanks immensely to the input from Monsignor Charles J. Fahey and Ms. Cleonice Tavani, the Report's principal writer, it is the Council's hope that the Frail Elderly Report will prove useful in advancing the knowledge and understanding of policy issues relevant to the oldest.

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FOR "THE FRAIL ELDERLY"

FCA RECOMMENDED CORE SERVICES

THE FEDERAL COUNCIL ON THE Aging has been particularly concerned, since its formation in 1974, with the problems of that group of the elderly -- usually the oldest of the old -- which it has come to call "the frail elderly".

This target group consists of persons, usually but not always, over the age of 75, who because of the accumulation of various continuing problems often require one or several supportive services in order to cope with daily life. They are expected to become a sizable percentage of this country's population well before the end of this century.

Concern is being expressed for this population in many quarters. They comprise the major age grouping in nursing homes. Dissatisfaction with the quality of care in a number of these institutions is responsible for the veritable avalanche of proposals for improving institutional care -- and possibly avoiding it with community-based alternatives.

The Federal Council on the Aging believes that there are no simple approaches to financing, planning, and delivering a package of services to these frail older persons. The Council does not necessarily conceive of these as health services. Other major program areas in the Federal government, such as social services, income maintenance, and housing, are equally involved.

Efforts toward solving this problem have all too often been short-ranged and narrowly focused. Many are based on medical models which do not address overwhelming social needs. Inadequate income is often used as a major criterion for eligibility for assistance, thus ruling out -- or at least discouraging -- persons who have been lifted out of poverty by recent improvements in benefit programs but who have inadequate coping skills. These will-intentioned efforts have often resulted in duplicative and administratively-ponderous programs which fall short of an equitable and effective distribution of government and philanthropic dollars. Nor do these efforts systematically begin with the minimum government aid needed to make maximum use of an elderly person's own resources and the voluntary assistance that might be available from family, friends, or philanthropic sources.

PROPOSAL FOR SERVICES TO THE FRAIL ELDERLY

The Council's recommendation for systematizing aid to persons who need direct personal assistance from society on a continuing basis is for a free - standing case assessment and case management service as an entitlement to the frail elderly upon reaching a certain age, on a national and voluntary basis. Frail persons below the age set could be qualified by some functional eligibility determination. This essentially social model should be complementary and of equal stature to services designed to meet the long-term health care needs of this population.

This "floor" of social services would provide a skilled practitioner to develop a plan of care in conjunction with the older person and his or her family and/or friends. A priority in the assessment and plan process would be identification of a "significant other person" (or persons) available to the frail older person to assist in coping with daily needs. The practitioner should see to the provision of such a "significant other" if none were already available. Case management would be an on-going service -- its intensity dependent upon the needs and wishes of the older person and his or her family and/or friends.

Major Principles of the Proposal*

A. FRAIL POPULATION

There are many persons within the aging populations who, because of an accumulation of various continuing problems, require the assistance of a significant person from time to time to aid in coping with certain daily life activities.

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*Adopted by the Federal Council on the Aging, September 1977

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B. GOVERNMENT ASSISTANCE

Where there is limited or no continuing availability of a significant person, certain aids for life management should be assured by government if agreed to by the frail person.

C. CORE SERVICES

The Federal Council on the Aging proposes that this assistance be available on a universal basis as an entitlement and be primarily of a social support nature consisting of the following services: case assessment, plan of care, and case management.

D. ELIGIBILITY

The core services should be available on the basis of presumptive eligibility, determined on the basis of attaining a certain age; e.g. 75. Persons below that defined age with need for these services should have access through some form of functional assessment.

E. ADMINISTRATION

The core services should be administered by a single state agency with Federal/State matching funding and flexible delivery at the community level.

F. SIGNIFICANT PERSON

When a significant person is not available or has not been identified through the case assessment, priority in developing the plan of care should be given to the provision of such a person.

G. REFERRAL

Any other services identified as being needed or desired are to be obtained from informal or formal services and benefits available to older persons.

H. UNMET NEEDS

A mechanism should be developed for providing data about the unmet needs of the frail elderly to community planning agencies and leadership/advocacy groups.

In support of its recommendation, the Council points out: there is adequate evidence of a serious gap in national policy and program attention to the frail elderly in the United States -- individuals with substantial impairments who are generally, but not exclusively, aged 75 years or over.

Present long-term care policy vis-a-vis the frail elderly is deficient in several ways, including: (a) a tendency to ignore the frail elderly living at home whose best interests may be served by remaining at home; (b) the imposition of a means test as a condition of receiving all long-term care; (c) an inadequate commitment to home and ambulatory health and social supports; and (d) a neglect of the social needs of the frail elderly in health programs offering long-term care.

Services to the frail elderly will be immeasurably strengthened by establishment of a core of basic support services which rests on a systematic assessment of the health, social, and environmental conditions of the frail older person; a coordinated service plan; counselling to provide both service coordination and linkage to other available services and provision of a significant other person when indicated.

The core program is to be made available without recourse to a means test and is to be voluntary on the part of frail older persons. Such a national policy and its program counterpart are likely to enhance the autonomy of the frail elderly and are designed to supplement rather than supplant assistance provided by family and kin or other elements of the natural helping system.

The proposed service should be provided through an agency or organization of national scope acceptable to frail older Americans.

Goals of the Service

Goals for the proposed services, stressed by the Council during the program's development, follow:

1. To assist the frail elderly to pursue reasonably independent and satisfying lives in their own places of residence.

2. To support frail elderly, with apparent impairments, striving for a normalization of family and social relations, by enabling such elderly to continue in their preferred environment and continue to make the critical decisions affecting their personal welfare.

3. To stimulate improved integration of preventive, ameliorative and supportive health and social services from community-based, state and national programs and resources.

4. To stabilize or eliminate actual or potential social isolation of the frail elderly without family or kin.

5. To utilize and integrate the respective contributions of family members and the formal helping network, along with efforts of the elderly for self help, to deal with the multiple needs of extended care associated with frailty in the later years.

6. To make more appropriate use of institutionalization so that such care will be reserved for those who clearly need it.

OTHER FCA ACTION

The Federal Council, influenced by its study of the needs of this most vulnerable group among the elderly, has also taken formal action in two related policy areas -- welfare reform and national health care.

On welfare reform, the Council's position is that there should be no reduction in the Supplemental Security Income (SSI) benefit of elderly recipients because they reside with a relative. It feels such living arrangements should be encouraged rather than discouraged.

On national health care and the elderly, the Council has adopted "principles" including the following important section on long-term care:

> Long-term care has two major components - medical and social. The long-term care medical system and benefits should reach all whose primary need is a medical regimen (in their own homes or in a medical facility). The long-term care social support system and benefits should reach all whose primary need is social support. In such a system, the medical component (both services and financial support) should be an integral part of the national health program. As a matter of national priority, a social-support system should also be developed to complement the national health care system, with both systems designed for implementation on the local level in a

simple, comprehensive fashion.

Minority Aged and Age-Related Elgibility

A consideration of how the Federal Council proposal for the frail elderly will affect aged minority persons has been made part of a study being conducted by the Human Resources Corporation of San Francisco through a contract with the Federal Council.

Concern has often been expressed that programs designed to benefit persons at a certain advanced age can be discriminatory to minority individuals because most of their sub-groups experience shorter life expectancies then their white counterparts. Because of this and other concerns relating to the minority elderly, the study has been undertaken to provide information about the equity and impact of age eligibility in relation to the FCA frail elderly proposal and for all major Federal programs. The Council is also sponsoring a study on the health manpower needs of the elderly, which includes an examination of the special health needs of the oldest of the old and manpower requirements necessary to serve them. Both studies are to be completed in 1978.

Next Steps

Public policy initiatives for the frail elderly must go further than the core services proposed by the Federal Council. Certain specific benefits, additional income and housing assistance, and special health and social services should also be available to care for a group among the population evidencing ongoing inability to cope with the daily and ordinary vicissitudes of life.

While working on policy recommendations for a floor of social care for the frail elderly, the Council has continued to advocate improvements in income, health, housing and social service for all the elderly. The Council believes there should be no let up in efforts to assure that all older Americans have sufficient material resources and sound health aid in order that they may continue "the pursuit of happiness" throughout the longest of lives.

At the last Federal Council meeting in 1977, the Council discussed the need for national policy attention to the broader context within which the floor of social services for the frail elderly would hopefully be provided. The Council recognized that the problem was one which impinges upon the responsibilities of many agencies and departments of government.

In view of these considerations and taking note of the fact that its Chairman also serves as Counsellor to the President, the Council adopted a resolution requesting the Chairman to propose a coordinated effort at the highest level of government for developing long-term care policy in the United States.

ARRIVING AT THE RECOMMENDATIONS

THE FEDERAL COUNCIL on the Aging began its operation with a few specific assignments and a very broad mandate to be a spokesman for older Americans to the executive and legislative branches of government regarding Federal activities affecting the elderly.

In determining the best use of its energies and resources, Council members sought for themselves an advocacy role that would complement the roles of such national friends of the elderly as the Administration on Aging, the Senate and House units on aging, senior citizen membership organizations, professional associations, and special aging interest groups.

In that first year it decided to focus on two long-range matters affecting the elderly that were not receiving the prominence of national policy debate which they deserved.

- An income assurance system for all the nation's elderly, integrating Social Security, Supplemental Security income, private pensions with appropriate Federal safeguards, and other private income sources.
- A national policy for the frail elderly, encompassing the financing, planning and delivery of a package of supportive community services to those most frail among the elderly who need some ongoing assistance in coping with daily life.

In deciding to focus on "the frail elderly", the Council deliberately chose not to be limited to "nursing home reform", "alternatives to institutionalization", "deinstitutionalization", "home health care", and "continuum of care". These were the banners of many laudable efforts in 1974 attempting to get a handle on an emerging national dilemma--the best means of caring for a growing vulnerable segment of the American population. The Council felt its special contribution would be to take a broad policy perspective and to begin with the human beings needing care rather than the caring system.

So began a policy development process which, aside from the contribution it is hopefully making to national policy makers, gerontological practitioners and academicians, and, most importantly, to the frail elderly, illustrates the workings of a citizen advisory body in resolving the kind of complex social problem which this Nation will increasingly face.

First Steps

The Council established a Task Force on the Frail Elderly under the leadership of Monsignor Charles J. Fahey. Membership consisted of representatives of the Council's three standing committees, Frank Henderson, Bernard Nash and Hobart Jackson. The group received Council approval to hold a seminar of national experts in March 1975 in order to assist the Council in focusing on major issues. Individual dialogue by FCA members and staff was initiated with gerontologists and other officials inside and outside government. The task force developed an outline (Appendix A) as a systematic means of obtaining information. This guided the Council's work and was distributed widely in the field.

In a July 1975 memo, Msgr. Fahey summarized the areas in which he believed the Council's Senior Services Committee had substantial agreement:

- o Our description of frail elderly includes but is not limited to physical debilities. We have concern also about emotional impairment, as well as debilitating physical and social environments.
- o Basic services to the frail elderly should include:
    - a) A thoroughly professional "diagnostic" prescriptive, monitoring capability (used in a psycho-social rather than medical sense).
    - b) Case leadership and management capabilities.
    - c) The affording of the physical presence of "another" in a flexible manner in accord with the need of the frail person. Such a capability would extend to the provision of funds when necessary to purchase this "presence".

Monsignor Fahey went on to observe that the number of existing embodying significant elements of a social intervention model were relatively few. Trying to extrapolate cost data for the Council's proposals was virtually impossible, he reported.

The full Council approved this formula of needs and services at its September 26-27, 1975 meeting, describing it as a social-support system for the frail elderly which would be a complement to the medical-care system. The medical-care system would basically consist of care which had to be medically monitored, whether delivered in a hospital, nursing home or a person's own residence.

The social-care system, the Council felt, should be basically a public program, using community sponsored non-profit agencies. It would consist of a Federal, State and local network. Financing would be out of tax revenues, not insurance, with matching arrangements from the various levels of government to be determined. There would be universal entitlement for the client group, with individual cost-sharing on a self-declaration basis. Generally speaking, no capital funding would be provided in this social-care system but start-up costs should be available.

The 1975 annual report spelled out the Council proposals for a "basic core" of supportive social services which should be available to all frail elderly as an entitlement, regardless of their ability to pay. Comments were included about the feasibility of using existing systems for these services for the frail elderly:

- Health - The Federal Council feels that the American health-care system cannot deal with the chronic conditions of an increasing number of the elderly population. They need ongoing and less-structured social care arrangements and the Council is reluctant to add these essentially social services to the health-care system. Effective application of sophisticated medical technology requires precisely defined and costly treatment methods and highly skilled and compensated practitioners. The health-care system is not designed -- nor should it be, the Federal Council believes -- to deliver the long-term social supports needed by the frail elderly to enable them to cope with everyday living, to say nothing of negotiating the various programs available in the community for them.

- Mental Health - Many of the mental frailties of the frail elderly are going to require ongoing support, primarily of a social, environmental nature, which does not gibe with the major treatment goals of psychotherapy. Then too, there is the stigma of being labeled mentally ill when what you are is an 80-year old person whom time has given a well-defined personality.

- Public Social Services - These are characterized by eligibility linked to income and assets, while a system of social intervention and support is needed by many older persons who are not impoverished. The availability and level of public social services is highly discretionary on the part of State and local government.

This early Council report also touched on the feasibility of using a certain advanced age, for instance 75, as an administrative device for triggering access to the proposed services. It was postulated that since there seemed to be a correlation between advanced age and the number of debilities, using attainment of age 75 or 80 as an eligibility determinant would be useful in delivering the service. It would also assist in defining the population for planning and financing purposes. At the same time, the Council said it would explore the problems with using this kind of criterion for those older persons belonging to racial minorities with consistently shorter life expectancies than the majority white population.

Developments in 1976

In 1976, the Council retained, as consultants to the frail elderly project, Leonard Cain, Professor of Sociology and Urban Studies, Portland State University, Portland, Oregon, and William G. Bell, Director, Multidisciplinary Center on Gerontology, Institute for Social Research, Florida State University, Tallahassee, Florida. They were to assist staff in the preparation of a draft report which would expand on the Council's deliberations thus far through their own studies and thinking as well as drawing from relevant scientific and practice activities.

The draft was reviewed by Council members, government officials, and others in the field of gerontology. To obtain further reaction, Council members Charles Fahey, Carl Eisdorfer and Hobart Jackson, with Dr. Cain and Dr. Bell, made a presentation to the October 1976 annual meeting of the Gerontological Society in New York City. The Council felt the feed-back it was receiving on its preliminary position affirmed the appropriateness and timeliness of the Council's initiative to generate a new national policy on the frail elderly.

With its work on the frail elderly serving as just one means of affecting another major Council goal of better systematizing Federal services and benefits for older Americans, the Council gave particular attention to the National Meals on Wheels Act which would amend Title VII of the Older Americans Act. At its September 1976 meeting, the Council took a position supporting home-delivered meals as an essential element of a program of ancillary services for the homebound. However, the importance of having a competent assessment and case management program in place first, was stressed. This would assure that a home-delivered meal or any other individually delivered service of any nature was appropriate.

The goals of services for the frail elderly, listed on pp. 4,5 were largely worked out in time for inclusion in its 1976 annual report.

A Year of Refinements

During 1977, the Council set for itself the goal of further refining its proposals for the frail elderly and relating them to other policy efforts of the Council. A special project involved the Gerontological Society. Its Section on Social Research, Planning and Practice expressed an interest in making "the frail elderly" a theme for its year's activities. The FCA/Task Force on the Frail Elderly met Section leaders during the summer to plan a series of theme meetings at the Gerontological Society's annual program meeting in November in San Francisco.

To focus the papers prepared for the meeting, FCA staff prepared a set of major "hypotheses" and accompanying questions (pp. 165-170) which were distributed to leaders of the Gerontological Society's Section.

By the time of its own September 1977 Council meeting, FCA members were ready to approve the major elements of the FCA frail elderly proposal now being readied for executive, legislative, and judicial action.

This description of the process involved in the development of a social policy initiative by the Federal Council on the Aging cannot possibly capture the many contributions of workers in the field of aging who generously shared their views and reactions with Council members and staff.

It is too early to measure the impact which the frail elderly proposals have had and will have on gerontological practice, research and legislation as the Council's work is not yet finished.

IDENTIFYING THE FRAIL ELDERLY

The Federal Council believes that an informed national policy on the aging requires this country to begin identifying groups within the large mass of individuals labelled "elderly." Msgr. Charles J. Fahey, Chairman of the Task Force, conveyed this view:

> "Age sixty-five" became embedded in public policy and in the cultural value system at the time of Bismarck with the development of the social welfare programs that he inaugurated as a government responsibility. Inasmuch as "65" became the fixed age for benefits, it became a bench-mark as far as perceptions and treatment of the elderly were concerned.
>
> Now, a century later, despite changes in life expectancy as well as the generally improved physical and psychological well-being of people over 65, it has remained firmly entrenched not only in our statutes but also in our culture as the critical determination of a new and inevitably deteriorating phase of the life cycle. Social scientists note that this phenomenon has had the effect of a self-fulfilling prophecy, however wrong the basic premise....
>
> This particular approach not only impinges on the well-being of individuals, but, unfortunately, may also skew our overall approach to public policy. Most statutes treat all persons over 65 as if similarly situated, despite the fact that there is an increasingly large reservoir of data indicating that within this group there are significant sub-groups having quite differing needs. Much of the argumentation presented in favor of or opposed to a program considers persons over 65 as being relatively homogeneous.

The Council is advancing the premise that the group of elderly beginning at age 75 should be viewed as a target population with special needs by reason of their vulnerability. After review and analysis, the age threshold of 75 withstands scrutiny since the evidence indicates that increasing age correlates positively with increasing functional impairment among the wider population of elderly.

Also, there is basis in law for development of a two-tiered age-status for older Americans. Leonard D. Cain, reporting on "Aging and the Law" in a Handbook of Aging and the Social Sciences published in 1976, wrote:

> The specification of a chronological age or age span for the purpose of status demarcation and differentiation is replete in the statutes, codes, and other legal expressions of a wide variety of governmentally validated agencies. Eligibility to vote, to receive a pension, to seek public office, to maintain the right to employment, to receive various protections or services or exemptions is typically determined in part by the chronological age of members of a society. References to age-related attributes (minor, elderly, grandparent), without specificity of chronological age, also abound.

There are problems with using a specific age as the doorway of entitlement to a defined set of supporting services for the frail elderly. It should be public policy to bring about adequacy and equity for all who are at similar risk. However, these goals cannot always be met in a single or the same program. In implementing a national policy, administrative considerations require specificity and simplicity with regard to eligibility to the program. Therefore, it sometimes becomes necessary to use certain criteria such as "age" status in order to target benefits recognizing that such a strategy will not be a full solution for persons who have additional minority "statuses". The Council will continue to examine this issue.

CHARACTERISTICS AND STATISTICS

The following data provide reasonable evidence that frailty is an accompaniment, however unwelcome, of increasing age. By frailty is meant reduction of physical and emotional capacities and loss of a social-support system to the extent that the elderly individual becomes unable to maintain a household or social contacts without continuing assistance from others.

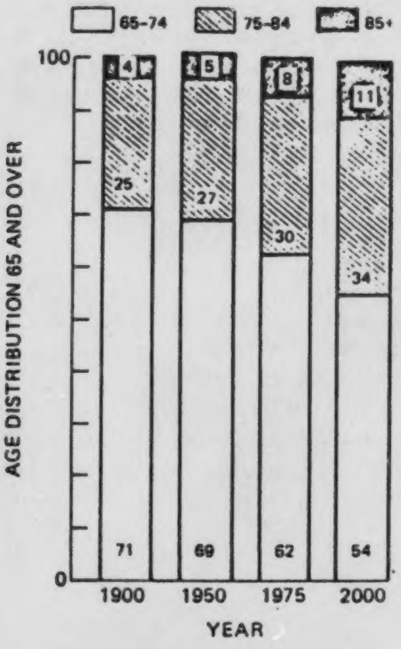
Increase in Numbers of the Oldest

Between 1977 and 2035, the total population in the United States is projected to grow by about 40%, from 217 million to 304 million persons. The elderly population is projected to more than double in size during this same period from 33 to 71 million persons. The segments of the elderly population that will be growing most rapidly will be the oldest of the old, women and persons of races other than white -- the same groups that have suffered more from such common problems of the elderly as poor health, social isolation, and poverty.

The population 75 years of age and older has experienced a ten-fold increase since 1900 and the age group 85+ has grown by about seventeen times while the size of the 60-and-over population has increased by nearly seven times. Currently, about nearly 40% of the elderly population is 75 and over, and this proportion is expected to increase to 45% by the year 2000. The 85+ group now constitutes one of every sixteen elderly persons; by 2000 they will represent one of every eleven.

FIGURE 1

The Percentage of the Very Old Among the Elderly is Increasing*



Note* Figure rounded to nearest total percentage.

SOURCE: Bureau of Census, *Current Population Reports*, Series P. 23, No. 59, May 1976.

Sex and Family Composition

The older population is predominantly female; the older the age group, the greater the predominance. In 1975, the 75-79 age group had 1.5 million males, 2.4 million females; the 80-84 age group had 955,000 males, 1.6 million females; and among those 85+ there were twice as many women as men. In the year 2000, there will be 154 women per 100 men 65+ and the 75+ ratio will be 191 to 100.

Since women in America typically marry men older than themselves, and since women outlive men, widowhood is a probable status for females in old age. In 1976, most older men (79%) were married: most older women (53%) were widows. The rate of widowhood rises from only 23% for women 60-64 years to 70% for those 75 years and older. Widows constitute over one-half of the total nursing home population and three-fourths of all elderly women in these institutions.

The fertility of successive age cohorts of women has varied greatly. For example, women who are now entering their mid-seventies have had fewer children than any age cohort before or since. Women now in their fifties, and expecially those in their forties, (the mothers of the so-called "baby boom,") abruptly reversed the long-time trend towards lower fertility. The mothers and fathers of the "boom babies" can look forward to having more adult children to rely on in their later years.

This, other related trends, and increasing longevity will mean that four - and five-generation families will become as common in the next century as the three-generation family has become today. Society has yet to assess the quality of relationships between and among generations because the phenomenon of more than three-generation families has never occurred before in such statistically significant numbers.

For instance, in 1900 there were only 21 persons 80+ for every 100 persons aged 60-64 and in 1950 the ratio was only 28:100. By 1980 the projected ratio will be 49:100. This does not present the entire picture of familial, intergenerational dependency because many 80 year-olds have offspring younger than 60 and "families" can include siblings, nieces, nephews and cousins.

Military Service

In identifying characteristics of older men, the fact of military service must be considered, especially in relation to benefits for which veteran status provides eligibility. (Women veterans amount to less than 2% of the current total.) Most World War I veterans were aged 65 to 75 years between 1960 and 1970 and aged 75-85 between 1970 and 1980. The World War II - Korean War veterans are a uniquely large group. By the year 1990 over half of all American males 65+ will be veterans, and by 2000 the percentage increases to almost 60% or 7.1 million men. Should current eligibility rates prevail, 250,000 of this next generation of elderly veterans will require VA nursing home beds (Senate Committee Report on Veterans Health Care, 1977).

There are few objective criteria for determining emotional well-being of men and women or differences in the quality of mental health between the sexes. However, differences in the suicide rate between older men and women are so marked that they bear further study for their implications in determining any national policy for the oldest of the old. With advancing age, there is a gradual increase in the rate of suicides for the total population but the rate for women decreases. For the group aged 60-64, there are three male suicides for one famale. Men aged 85 and over commit suicide at the rate of 10.5 to one woman in that group.

Educational Attainment

The number of years of education one receives remains a consistently effective index of economic and social well-being. Between 1940 and 1976, the median number of school years of persons 25 years old and over rose steadily from 8.6 to 12.4 years. Since 1960, the median for the elderly has risen from 8.3 to 10.3 years, and this figure can be expected to rise to 12 years around the year 1990. Although the overall median for the elderly population was 10.3 in 1976, this figure ranged from 12 years for the 60-64 age group to about 9 years for persons 75 and over.

Related to the increase in educational attainment is the decrease in the number of elderly persons with language difficulties. A survey conducted in 1975 by the Census Bureau indicated that 5%, or one million persons 65 years of age or over, usually spoke a language other than English. The usual speaking language for half of these persons was either Spanish (30%) or Italian (20%).

Race/Ethnicity

There is an increasing awareness of the importance of identifying racial and ethnic factors in order to understand both the problems and the strengths of older Americans. Ethnicity is described (Giordano and Levine, 1975) as more than a distinctiveness defined by race, religion, national origin and geography. "It involves conscious and unconscious processes that fulfill a deep psychological need for security, identity and a sense of historical continuity. It is transmitted in an emotional language within the family and is reinforced by similar units in the community. Thus, there is a significant interrelationship between ethnicity, family and neighborhood".

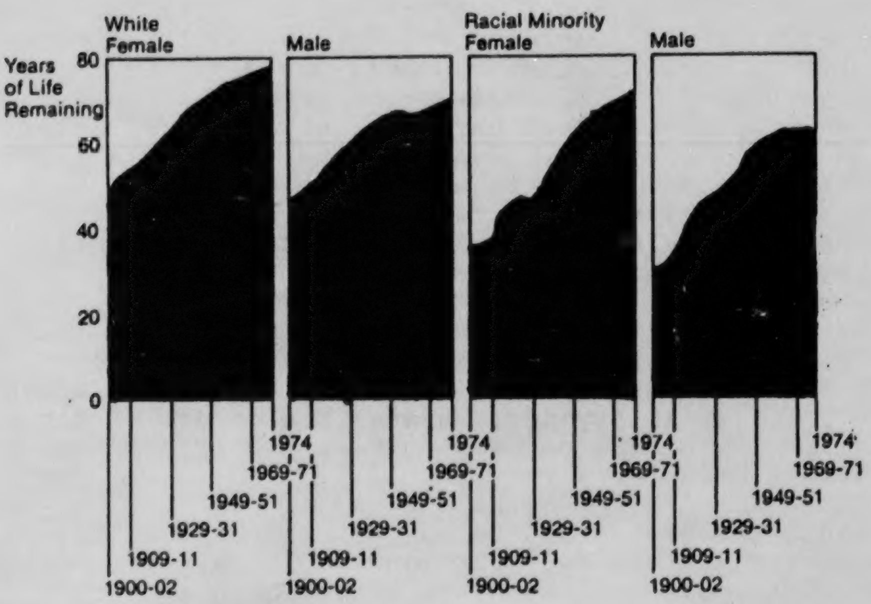
Nearly one-fifth of American citizens now 75 years of age and over were immigrants to this country. Most were post-World War I immigrants from Southern and Eastern Europe. Demographers are still trying to assess the impact of the current influx to the USA of persons from countries south of our territorial borders.

Available research seems to suggest there is little correlation between race and functional ability. Yet most racial minorities have shorter life expectancy rates than whites. (Figure 2 - following page)

(Figure 2)

Life Expectancy—Race and Sex

Estimated Average Length of Life in Years,
by Race and Sex: Death Registration States, 1900-1928,
and United States, 1929-1974



Source U.S.P.H.S., National Center for Health Statistics, Vital Statistics of the U.S., 1974, Vol. II, Section 5. In preparation.

These differences in life expectancy between whites and racial minorities are usually attributed to lower socioeconomic status. The next table (Figure 3) provides futher evidence of the disparity in wealth and life expectancies among the various racial/ethnic groups in this country.

Figure 3

FROM: Human Resources Corporation, Theories of Social Gerontology for Research and Programming by the Administration on Aging, Volume One: Final Report, San Francisco, CA, March 1976.

SELECTED CHARACTERISTICS OF RACIAL/ETHNIC AGED POPULATIONS (65 AND OVER), 1970
(See notes on following page.)

Characteristics	Total Elderly	White	Black	Spanish Heritage	Spanish Nationalities			Asian Nationalities			Native American
					Mexican	Puerto Rican	Cuban	Japanese	Chinese	Filipino	
Number (in thousands)	20,050	18,360	1,586	382	189	34	35	47	27	21	44
Percent of Total (all ages)	9.9	10.3	6.9	4.1	4.2	2.4	6.4	8.0	6.2	6.3	5.7
Median Age of Population	28	29	22	22	19	20	32	32	27	26	20
Age 75 and Over as % of all Elderly	38.1	38.6	33.4	32.4	32.5	32.7	33.8	41.2	30.0	20.8	35.2
Sex Ratio (men per 100 women)	72	72	77	90	95	74	64	77	131	445	92
Percent living in:											
Urban areas	73.0	72.6	76.6	86.3	86.3	98.0	98.5	84.8	97.0	77.9	42.7
Rural, non-farm	21.5	21.7	19.5	11.7	12.0	1.8	-	11.7	2.5	18.6	50.2
Rural, farm	5.5	5.7	3.9	3.5	1.7	0.2	-	3.5	0.5	3.5	7.1
Percent Poor	27.3	25.3	49.3	32.2	36.7	29.1	24.3	20.0	28.9	25.3	50.8
Percent in Labor Market											
Men	24.8	24.9	23.5	24.8	24.1	22.6	32.6	29.3	24.8	32.1	17.2
Women	10.0	9.8	13.2	7.9	7.4	8.5	5.5	12.0	12.0	11.4	8.5
Percent Completed High School											
Men	26.0	25.8	8.9	15.8	6.4	14.6	38.0	27.3	21.3	17.3	11.0
Women	29.8	30.6	11.5	15.5	7.4	9.2	21.5	25.4	15.5	16.6	14.9
Percent Married & With Spouse											
Men	68.4	69.5	54.5	63.8	60.6	55.7	74.1	68.0	52.9	40.9	57.3
Women	33.7	37.6	21.5	30.8	19.7	25.2	12.4	32.4	35.2	36.6	23.2
Percent Widowed											
Men	18.0	16.5	31.9	18.2	32.8	21.9	25.9	16.5	19.4	14.2	32.8
Women	54.6	56.4	67.2	53.2	51.8	57.6	53.5	57.9	52.8	39.7	52.4

Figure 3 (continued)

SOURCES. U. S. Bureau of the Census, *Census of Population, 1970. General Social and Economic Characteristics, Final Report PC(1)-C1 United States Summary* (Washington, D. C.: USGPO, 1972); __________, *Census of Population, 1970. Subject Reports, Final Report PC(2)-1C, Persons of Spanish Origin* (Washington, D. C.: USGPO, 1973); __________, *Census of Population, 1970. Subject Reports, Final Report PC(2)-1F, American Indians* (Washington, D. C.: USGPO, 1973); __________, *Census of Population, 1970. Subject Reports, Final Report PC(2)-1G, Japanese, Chinese and Filipinos in the United States* (Washington, D. C.: USGPO, 1973); __________, *Census of Population, 1970. Subject Reports, Final Report PC(2)-9A, Low Income Population* (Washington, D. C.: USGPO, 1973).

NOTES. Racial/ethnic populations:

Total elderly includes all persons 65 years of age and over.

White, Black are mutually exclusive categories. Term "Negro" is used in census publications.

Spanish Heritage includes persons with Spanish surname, Spanish as mother tongue and/or Spanish origin. Also included in white and black populations on basis of self-reporting or country of origin.

Mexican, Puerto Rican, Cuban--categories based on country of origin of reporting person by place of birth for self or parent(s). The sum of the three categories does not equal Spanish heritage.

Japanese, Chinese, Filipino--categories based on country of origin of reporting person by place of birth for self or parent(s).

Native American includes persons identifying self as American Indian or giving name of tribe.

Characteristics:

Percent poor is calculated on basis of level of income of unit within which individual lives--if in family, based on level of family income.

In labor market includes persons working or looking for work.

Income

Facts about total money income per year do not convey adequately the actual economic well-being of classes of individuals, including the elderly, since assets, government benefits and services, and in-kind services and assistance from relatives and friends are not included. However, data about income can still assist in understanding the special needs that accrue with older age. Differences between those 65-72 and those 73+ who are in comparable family circumstances point to the vulnerability of the "frail elderly". For married couples aged 65-72, median income in 1973 was $6,691; for those 73+, $5,084. Where 46.9 percent of the younger-old had at least $7,000 in income, only 29.7 percent of those aged 73 and over had comparable amounts.

Single males 65-72 not in families had a median income of $3,542; those 73+ only $2,882; among females, the younger elderly had $2,915, the older only $2,471. Over one-half (51%) of females 73+ had money income of less than $2,500 in 1973.

Recent improvements in Social Security benefits and such income support programs as Supplemental Security Income, food stamps and housing subsidies have caused a decline in the total number of the elderly poor. However, subgroups that experienced slower rates of decline in poverty, or no decline at all, were those same subgroups that were growing in size most rapidly and are projected to continue growing at rapid rates: females, minorities and those who live alone. Women and minorities tend to have worked less in the past and to have worked in lower-paying occupations than white males, and, therefore, tend to have fewer financial assets to rely on after retirement.

It is likely that the income and other financial resources of most of the future elderly will be greater than those of today's elderly. Tomorrow's elderly will be more highly educated and will have worked in higher-paying occupations. A higher proportion of elderly women in the future will have participated in the labor force for a significant number of their preretirement years, and will, therefore, be receiving retirement benefits of their own.

With advancing age, some older persons experience difficulty in managing money. When all or part of their income is derived from some government income transfer program, certain procedures must be undertaken to assure the use of the monies for the well-being of the intended beneficiaries. The Social Security Administration and the Veterans Administration appoint "representative payees" for persons they believe cannot manage their own cash benefits payments. In a way, the need for this designation is another indicator of frailty.

Figure 4

Social Security Beneficiaries with Representative Payees

Age	Percent
65-74	.7
75-84	1.9
85+	6.6

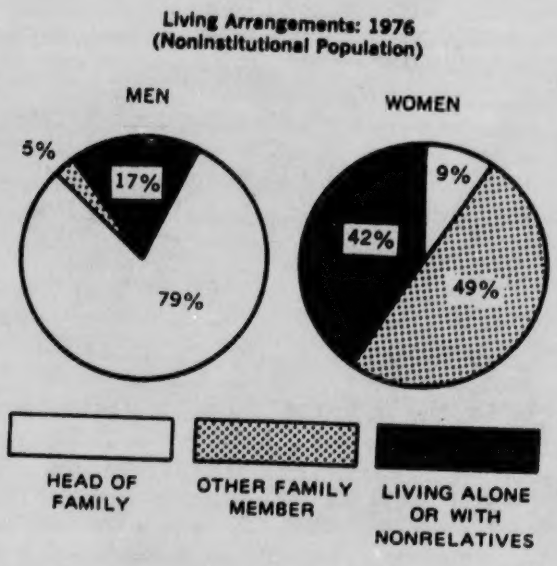
Source: Adapted from Social Security Bulletin, Vol. 40, No. 9, September 1977

Data are not available on the number of SSI recipients who have other persons officially responsible for handling their benefits, except for those persons who are residing in domiciliary care facilities and receiving federally-administered optional State supplements. Of persons 65+ in such supported living arrangements, 15 percent had representative payees, almost half of whom were relatives. The aged with representative payees were predominantly those 75 and over (72.9%)

Living Arrangements

Numbers of older men and older women living in a family setting in 1976 were about the same, 7.4 million, but since there are many more older women than older men, the proportion of older men in family settings was 83% and that of women, only 58%.

Figure 5

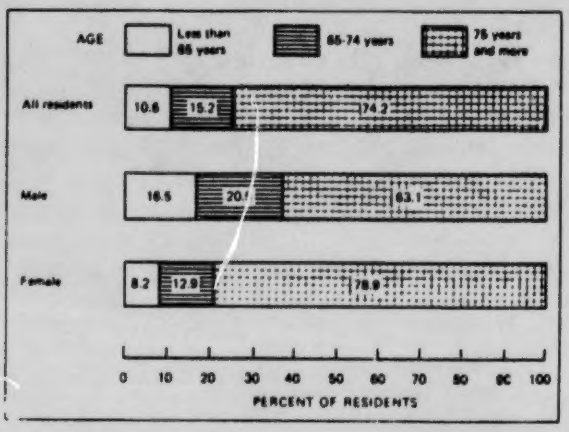


Source: "Facts About Older American 1977", Administration on Aging, HEW.

About 5% or approximately one million older people lived in institutions of all kinds in 1976. (In 1985, the institutionalized population is expected to be 2.6 million). Seven out of 10 nursing home residents are women. Generally, there were 238 females per 100 males. Of female nursing home residents, almost 80% were aged 75 or over. About 63% of the male nursing home residents were 75 years or age or over.

Figure 6

Percent Distribution of Nursing Home Residents
(August 1973 - April 1974)



Source: Vital and Health Statistics - Series 13 -
No. 28, DHEW Publication No. (HRA) 47-1779, p. 5.

Location

Although there is the widespread notion that the elderly are a migratory group (moving to a warmer climate, for example, upon retirement), the fact is that the older population is the least migratory of any age group. Between 1970 and 1975, over 40% of the total U.S. population moved to a different residence. Among the 65-74 years of age, moving was at the rate of 20% and for those 75+, slightly more than 18%.

The special problems of the elderly residing in rural areas have long been a concern of the Federal Council and many other advocates of the elderly. Inadequacies in transportation and formal health and social services have been documented. While many believe the quality of informal rural supports from such sources as neighbors is superior to that to be found in the urban environment, others believe that the departure of younger generations to the city to make a living denies frail older relatives the familial aid they will need with advancing years. But just as the migration from the farm to the city has stabilized, so too is the urban componenent of the older population expected to remain at 70% at least until the year 2000.

Well-Being of the Elderly

It is a fact that each person ages differently and the interaction between physical and mental health and between health and social and environmental factors all affect the measurement of "well-being" among the elderly.

Two recent efforts to measure the overall condition of the elderly are most useful for planning and policy efforts such as the Federal Council on the Aging project on the frail elderly.

The studies of Saad Nagi (1975) show the following rates of limitations in physical and emotional performance and on independent living by age:

Figure 7*

Respondents by Age	Minimal Limitation	Some Limitation	Substantial Limitation	Severe Limitation
Limitations in Physical Performance by Age, by Percentage				
65-74	56.4	23.7	9.7	10.1
75+	29.7	27.9	22.5	19.9
Limitations in Emotional Performance by Age, by Percentage				
65-74	32.1	35.2	22.6	10.1
75+	25.5	39.3	22.2	12.9

Limitations in Independent Living by Age, by Percentage

Respondents by Age	None	Limited but Independent	Mobility Assistance Needed	Personal Care Assistance Needed
65-74	77.4	11.1	8.5	3.0
75+	59.5	14.7	16.7	9.1

*Adapted from Nagi, Saad, *An Epidemiology of Adulthood Disability in the United States,* Mershon Center, Ohio State University, 1975.

The General Accounting Office used the OARS Multidemensional Functional Assessment survey instrument (Pfeiffer, 1975) to determine the well-being status and impairment level of older persons in Cleveland as part of its study described on pages 76,77 GAO combined its data and material resulting from the development of the instrument at the OARS - Duke project to provide the following table:

Figure 8

Impairment level	Noninstitutionalized people		Institutionalized people	
	(percent)			
Unimpaired	21	86	1	13
Slightly	21		1	
Mildly	18		2	
Moderately	17		5	
Generally	9		4	
Greatly	7	14	11	87
Extremely	7		76	
	100		100	

The OARS survey asks questions in five areas of human functioning: social, economic, mental, physical and activities of daily living. The results in each area are combined to form a picture of overall well-being. The scale begins with "unimpaired", which means excellent or good in all five areas of human functioning. At the other end of the scale, "extremely impaired" means mild or moderate impairment in four areas and severe or complete impairment in the other, or complete impairment in two or more areas.

At the request of the Federal Council on the Aging, the GAO prepared special calculations (Figure 9) based on its Cleveland study to show the relationship between advanced age and a decline in well-being status. It notes the almost doubling in the "extremely impaired" rate between the 75-79 age group and the 80-84 group.

Figure 9

DETAILED BREAK-DOWN OF WELL-BEING STATUS BY AGE

	Percent of age group				
Well-being status	Under 70	70-74	75-79	80-84	85+
Unimpaired	25.8	20.5	14.9	8.7	9.2
Slightly impaired	25.1	25.0	15.7	15.0	11.2
Mildly impaired	19.2	19.5	21.0	21.4	22.5
Moderately impaired	13.7	12.1	22.6	17.9	14.3
Generally impaired	5.4	10.8	9.3	11.6	12.2
Greatly impaired	1.9	2.9	3.6	2.9	2.0
Very greatly impaired	2.6	2.4	3.6	4.6	6.1
Extremely impaired	6.3	6.8	9.3	17.9	22.5
	100	100	100	100	100

The GAO was also asked by the Federal Council whether minority elderly revealed more severe impairments at younger ages then whites. According to GAO data, minority (black) persons did experience more severe impairments at lower ages. However, there was no statistically significant difference for those persons 75 and over in the two racial groups.

Conclusion

There is sufficient evidence regarding both physiological and social decrements to support the conclusion that it is no longer sufficient for national policy on the elderly to be based on the following premises:

- All those past 65 (or 60) fit into a single old age status or category.
- The national strategy of income maintenance, which may serve the younger, well and mobile elderly, is not adequate for the older and frail.
- The present haphazard array and the uneven availability of health and social services create additional needs for persons, already functionally impaired to a considerable degree, who cannot broker their own services and benefits.

Evidence does support a policy based on the following:

- A second older-age status, with the presumption -- for administrative purposes -- of frailty at a certain advanced age, is needed and equitable.
- A strategy of social intervention is needed for the frail elderly to provide services not avialable in the market place.
- A pattern of social services based on automatic entitlement is needed to assure access to services by all those who become frail.

TODAY'S SITUATION - THE HELP THAT EXISTS

THE NEED FOR "help in getting help" has been recognized. The Older Americans Act, particularly through the area agencies of aging, attempts to bring about agency cooperation at the community level to provide comprehensive, coordinated services for the elderly. There are now federally-aided mechanisms for health and social service planning for people of all ages at the local and State levels. There have been a number of demonstration projects where coordination begins with the individual needing help rather than the helping agency.

The array of Federal benefits and services which are available to the elderly is in many ways a measure of the compassion which this Nation does have for the elderly and shows an attempt to meet some of their specific needs.

But the unevenness and confusing and often conflicting eligibility requirements of the programs reflect both the best and the worst of the democratic process and of a highly developed nation. They show the democratic process responding to the laudable pressures of citizens organized around a particular issue and the response of members of the House and Senate organized into committees with unyielding jurisdictional lines around each domestic program area. And they show the highly developed nation with all of its servants, civil and otherwise, seemingly unable to apply its modern technologies to the efficient and effective delivery of needed help to its least fortunate citizens.

FCA Study:

Interrelationships of Benefit Programs

The Congress has become increasingly concerned about the individual citizen who is faced at the community level with both a confusing array of certain aids and the absence of many needed benefits and services. To try to resolve the problems which occur when the receiving of one Federal benefit cancels eligibility for another, the Congress asked the Federal Council to study the matter and come up with some solutions.

The resultant FCA report, "The Interrelationships of Benefits Programs for the Elderly" (1975) found that, in that year, approximately 22 percent of older Americans would receive assistance from at least one of the three income-conditioned programs -- SSI, food stamps and Medicaid. Of these beneficiaries, 49% would be participating in only one program, 34% in two and 17% in all three.

The study also found that several benefit programs had low rates of participation and the FCA urged the Administration to:

- Learn the reasons for low participation as a basis for special efforts to inform and sign up eligible persons.
- Consider the feasibility of a simplified system at the local level for determining eligibility and benefit levels for all federally-funded income-conditioned programs.

Information and Referral

The need for older persons to be informed about benefits and services to which they are entitled or which are available in their community is being addressed at the community level. Information and referral ("I and R") programs have existed for many years under voluntary, often United Way, sponsorship. The passage of the Older Americans Act in 1965 provided funds for a number of demonstration efforts for special I&R programs for the elderly. The 1973 amendments to the Older Americans Act mandated such programs as a basic service to be provided by the new area agencies on aging.

While such efforts are most useful to the vast majority of the elderly who can benefit from what is essentially a short-term service not requiring highly-skilled persons as the major practitioners, it is not enough for the frail elderly.

Legal Services

Subsidized legal services, have become available to the poor and the elderly, first through the Economic Opportunity

Act and then with the establishment of the Legal Services Corporation and legal services under the Older Americans Act. They have aided those who were denied or deterred from receiving certain services because of various legal barriers or interpretations by program officials. This advocacy in connection with particular legal problems of the elderly has been and will continue to be needed by many of the elderly and especially the most frail. But because their frailty is made up of so many factors and because the needed help must be equally multidimensional, legal services are not enough.

FAMILY SUPPORTS AND FAMILY SURROGATES

Every culture seems to have within its folklore, a variation of the story of the aging parent who laments: "How can one mother take care of ten children but ten children can't take care of one mother?"

Data emerging from a number of recent studies do not support this homely assessment of intergenerational reciprocity. Studies of the General Accounting Office, described in this report (pp. 76-81) and a number of academic researchers substantiate the fact that an overwhelming majority of adult children do "care" for and about their aged parents.

Generated largely by findings from empirical research, there is evidence of close generational ties within modern families. (Shanas & Streib, 1965)(Sussman, 1962). Consistent data on close family relations emerge from studies of families drawn either from middle or working class populations. Patterns of mutual aid and frequent contact between family members were viewed as indicative of family support and solidarity. An absence of shared households was believed not critical in relations between an adult child and aging parent not sharing a common roof. Repeated studies reveal at least one adult child tends to settle in reasonable proximity to the parental home to be available for assistance. Ethel Shanas, for example, found that approximately half of all aging parents in the United States live within a 10-minute journey of at least one adult child. Shanas reports further that 65% of the national sample of elderly interviewed in the United States reported direct contact with at least one adult child on the day or previous day of the interview. Researchers acknowledge some older people may be isolated or without family or kin but such aged persons in the aggregate constitute a minority of older Americans.

It is a challenge to identify changes in family functions because these are evolving so rapidly. Several recent developments which are associated with the modern era are the evolution of the two-generation nuclear family consisting of adult parents and their offspring of minority age; reduction of family-living-space evident in the size of urban apartments and houses generally; demands of the work system which require upwardly mobile families to move in accord with occupational demands of employers; and the demise of the three-generation family residing under a single roof.

Impact of Public Policies on Family Bonds

If one accepts the premise that public policies should enhance existing and encourage additional intergenerational help to the frail elderly, it is useful to assess the impact of previous public policy decisions regarding the elderly and the family.

In 1960, Alvin Schorr (of the Social Security Administration), evaluated the practice of filial responsibility in the United States and the relationship to it of social security programs. He observed that reliance on one's own income, even if it provides partial support, contributes to an aged person's sense of dignity and self-respect. A major form of aid to older relatives prior to social security had been shared housing. The income available through this social insurance program gave older people the option of independent living and many took it. When relations between adult children and their parents were based on at least partial independence, Schorr observed there was a spontaneous exchange of help and services.

Supplementing social insurances to assure a floor of income to the older generation must be recognized as a major motivation behind the federalizing of old age assistance through the Supplemental Security Income program. Acceptance of the notion that cash income aid between the generations should have such a degree of Federal involvement even extended to the elimination of any filial support provisions in SSI.

Some States still have vestigial filial support laws in relation to State supplements to SSI but it can be concluded that Americans no longer expect adult children to bear major financial responsibility for their aged parents.

There is also considerable consensus supporting the public policy embodied in Medicare that the acute health needs of the aged population should be met substantially by a Federal social insurance program. It is likely that help in meeting specifically defined health needs associated with chronically disabling conditions will also continue to have broad citizen support either through Medicaid or a new National Health Care program. Older persons and/or their families are not expected to shoulder these health costs alone.

But there does not seem to be any similar consensus about the nature, quality, and intensity of Federal aid which should be available to replace in whole or in part family roles and responsibilities in relation to older members who can no longer lead completely independent lives but do not require a continuing health regime.

Dorothy Rice and Saul Waldman* at a conference on long-term care in 1975 indicated that the present patterns of care by family are not likely to continue:

> While this type of (informal family) care is presently an important element, social and economic trends in our society -- greater geographic mobility of the population, the rise in employment rates of women, and loosening of family ties -- suggest reduction over the long-term....
>
> Without bringing in outmoded concepts of familial responsibility, a public long-term care program cannot exclude from eligibility for benefits those who have been receiving, or could receive, informal care.

The Federal Council has identified the need for frail older persons to have a "significant other" person in their lives and that government should assist to assure the availability of this person when necessary and appropriate. In a sense, "family" means at least two people who are bound in some form of mutual and significant relationship with each other. The dilemma in government assuring the availability of a significant other to a frail older person is the major dilemma facing policy-makers regarding long-term care. As a

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*In report of the Conference on Long-Term Care Data sponsored by Natl. Center on Health Statistics and Johns Hopkins Univ., Tucson, Ariz., May 1975.

Nation , we are just not sure how much and in what way government can and should take over traditional caring functions of the family for its frail members.

Government Aid for the Family-Caring Function

Robert Ball, (1977) has described this nation's policy for the elderly as primarily an income policy.

> Even our national health insurance plan for the elderly and disabled, Medicare, conceptually, has been an extension of retirement insurance, protecting the retiree against the cost of episodic illness on the rationale that such costs are unbudgetable and cannot reasonably be met by a regular monthly pension.

In developing a "service strategy" for aid to the frail elderly, it might be useful to work further with the "income strategy" toward goals of enhancing and establishing family-like arrangements of aid.

In examining the Administration's welfare reform proposals, the Council asked for cessation of the practice whereby SSI recipients residing in the household of another person have their benefit reduced by one-third on the basis of an imputed contribution.

A further step could be a modest "add-on" to SSI of around $40 to $50 a month (1978 dollars) to compensate family members, friends and/or neighbors for simple personal-care services. This would be a straight forward means of achieving the FCA goal of assuring and/or providing a "significant other" to aid in coping with daily living.

Utilizing the FCA proposal of advanced age as an indicator of need rather than poverty or functional impairment as in the previously described measures, this flat increment could be provided to all SSI recipients upon attainment age 75. The payment could be increased, for instance, at five-year intervals on the assumption that increasing age would require additional funds for aiding in provision of a significant person and for other life necessities.

For those not on SSI, the eligibility threshhold could be increased accordingly. As mentioned often in this report, having money is not always assurance that a frail person who is becoming mentally confused will be able to cope. But try money first, and then make a separate determination as to whether some form of "case management" is also needed in order to provide a "significant other".

In ongoing research by Marvin Sussman, the impact of a cash allowance to a family for care of an older relative is being studied. In a simulated situation, respondent families were asked whether incentives including cash would be a determinant in the decision to take in a near or distant relative. Sussman found that, at best, incentives facilitate the process and make it easier for the already committed and does little to change the minds of the refusers. His initial data suggest that most families (81 percent) will accept older people in the household in some circumstances. There is, however, a hard core of approximately 19 percent who indicated that they would not take in older relatives under any conditions.

R.M. Moroney (1977) suggests that low-interest loans to make physical adjustments and/or additions to the home would aid those families who want to take in their elders but whose housing is inadequate or inappropriate. He also proposes "respite care", that is, regular periods of time when someone will take over the caring function. This allows for vacations, rest, and a chance to do things that cannot be done with the constant care needs of the frail family member.

While case management is being covered in another part of this report, it is important to identify this service also as one for the significant other person(s) in the life of the older person. Counseling will be provided to this caring person as well as to the older person in coping with the exigencies of this living situation.

Impact of Changing Family Constellations

In designing plans to serve the elderly, it is vital to recognize that participation in kinship networks varies greatly among the frail elderly. Whereas, one older person may have a number of surviving siblings, offspring, and long-time neighbors and friends; another may be the last survivor, one whose relatives and friends have preceded him or her in death. Some who are frail remain married; some have been divorced or widowed, and some have never married at all. Some have children close by; others have been isolated for decades.

There is likelihood that onset of frailty in practical, program-requirement terms (operational frailty?) is "triggered" more frequently and more dramatically by changes in family circumstances than any other one change. That is, the need for services for a frail person is likely to become acute upon the death of a spouse, or when one spouse becomes bedridden or hospitalized, or upon the inability of a relative to continue to offer services informally.

In considering proper roles for family members and family surrogates in serving the frail elderly, there is need for a reminder that opportunity for nurture of the multi-generational family never before possible is now emerging.

Although the multi-generation family continues to be presented as the realized structure of past generations, facts are that three-, and certainly four-generation families, have been comparatively rare, and such families with members in close proximity rarer still. First, an immigrant nation leaves its older relatives behind. America has been an immigrant nation through the early years of this century. Nearly one-fifth of those now 75+ are immigrants. And few of their children have had contact with a grand-parental generation.

In addition, American society has been mobile, both vertically and horizontally. The vertical mobility of second and third generation immigrants and first and second generation migrants from sharecropper farms to the cities has produced intergenerational strains. The horizontal mobility, to eastern and northern cities, from east to west, from south to north and, more recently, from north to south, has resulted in separation by considerable distance of parents from their children and grandchildren.

The result is that America, in a sense for the first time in its history, has, structurally, three- and four-generation families, and has, socially, an opportunity to promote strong bonds among kinship members. A program for the frail elderly needs to consider the potentials of this emerging opportunity.

Importance of Ethnic and Cultural Distinctions

Another emerging opportunity for enhancing family care for its elders is to be found in the "roots" phenomenon. Alex Haley's book on his search for his African slave ancestors was just one manifestation of the growing interest in not just identifying one's lineage but in strengthening and utilizing affectional, cultural and ethnic bonds.

In a study nearing completion of policy issues concerning the minority elderly which was commissioned by the Federal Council on the Aging, it is being recommend that natural support among minority elderly be recognized and maintained, and that legislation, regulations and policies that may disrupt, eliminate or have a negative impact on these systems be identified and addressed.

This study, which was carried out by the Human Resources Corporation, compiled evidence that:

> ...in many minority communities, the elderly are not segregated by age, but are linked intergenerationally with the family and the community. It is imperative that these links and roles be recognized so that social services and government policies do not inadvertently supplant the role of the family and community, and that they do not force or foster segregation by age of elderly minority persons. Closely associated with this principle is the fact that the family plays a very important part in the emotional, as well as physical, security of the older person. Every effort must be made to work with the family and to bring the family in wherever social services are provided.

Creating Family-Like Living Arrangements

But what about persons without families or with families who cannot or will not provide a home and care? Nearly two-thirds of the States are adding funds to Federal SSI payments for persons residing in domiciliary care facilities. (Kochlar, 1977). Data which are available only for those States that have elected Federal administration of their optional program indicate 40 percent of the recipients were aged persons who received an average combined Federal-State payment of $205 a month.

It should be added that domiciliary care is for individuals who cannot function in an independent living arrangement. It may be provided in foster care homes, in family-type settings for fewer than five persons, or in a larger group or institutional setting. "Dom care", as it is called in Pennsylvania, is one means of reconstructing a family-like support system.

Different levels of supervision are available for these persons. Theoretically, all receive casework services from the State or local social service agency. Ambulatory individuals who need assistance with eating, bathing, or dressing but do not require regular medical or nursing care are given additional amounts of money in Hawaii, Massachusetts, Michigan, and New York. Individuals requiring a more protective setting receive custodial and other non-medical care in addition to personal care. These persons include, for example, the mentally retarded, former mental patients requiring special care or "individuals who are confused because of advanced age". Several of the States have payment schedules which also reflect these special circumstances. Some of the payments for these recipients are paid to representative payees.

Natural Helping Networks for the Elderly

Even with formal, organized social help and change efforts and sometimes, despite these efforts, informal systems of help in addition to family efforts have continued to flourish in almost all social communities. In examining recent studies, Beatrice Ferleger in 1977 concluded that an informal social support system - a natural helping network - exists for the elderly. This network helps to sustain elderly people both emotionally and physically and acts as a supplement to the formal system which often does not adequately meet their needs. Ferleger found that informal service providers -- relatives, friends and neighbors -- are frequently the primary support system of elderly people. They provide the linkage between the older person and needed social and health services.

From her examination of studies conducted by Cantor (1973), Heisel (1973) and Bild and Havighurst (1976), Ferleger makes the following conclusions regarding the natural helping networks:

> As far as policy is concerned, support of the informal system moves it in two directions: (1) toward a strategy of prevention, i.e., drawing on the knowledge of the natural helper increases the possibility that early identification and intervention will minimize and avert crisis situations and will serve a preventive function; and (2) toward decentralization of service delivery into the community.

> The orientation toward prevention and decentralized community-based service delivery in the utilization of the informal system necessitates the recognition that strengthening this system in no way obviates the need to strengthen the formal one as well ....For legislators, policy-makers and planners, this means that: planning should provide for increasingly available and accessible services in the community; the capacity to integrate service delivery should be increased, possibly by planning for the development of a decentralized case management system with authority and accountability; and legislation should stress and provide for preventive and community-based services.

A final word should be noted about the relationship between the natural helping network and the formal system. The natural neighbor-helper may see the representative of the formal helping agency as an intruder. The professional may have difficulty in moving away from traditional service delivery techniques and work in a peer relationship in an unstructured situation. Therefore, a high level of professional training and discipline is necessary to strengthen the natural system without disrupting its delicate balance.

Providing Family Surrogates

The proposal of a modest "add-on" to the SSI payment is an attempt to encourage and compensate the natural network of help in an older person's life when and where it exists. It might pay for the gas of a neighbor who will drive an older person to the clinic once a week and pay the teenager down the street for shoveling the snow off the front walk. It will not be enough to pay for a home health aid twice a week. When that level of care is required, the formal system of social or health services will have to be involved in order to make a determination of need. Policy-makers will not accept the provision of that level and cost of care without some individual assessment of functional need as well as income status, appropriate standards and a monitoring system.

Where the older person even with the additional SSI payment cannot identify or utilize a significant other, it would be the function of the case manager to bring this about. If family, friends and neighbors are not available, the case manager -- herself now a significant other person to the frail older client -- might turn to some organized volunteer program to recruit someone willing to provide some of these important personal care services like shopping and companionship in person or on the phone.

Organized volunteer programs abound in the voluntary sector sponsored by church, civic, fraternal and social organizations and the United Way. The following section describes the programs in which the Federal government has helped stimulate volunteer programs which are and could be particulatly helpful to the frail elderly in bringing a family surrogate into their lives.

In reviewing this proposal of the FCA, Dr. Ruth Weber speaking at the session on the frail elderly at the 1977 Gerontological Society, cautioned that the problems of training, supervising and matching the significant other to the older person are still being studied. "Most important is the lack of consensus about how the older person's decision-making is to be maximized in this situation."

Federally-Aided Volunteer Programs

Among the social initiatives of the Sixties was the concept of a modest subsidy to enable a person of limited income or a person who wanted only enough for subsistence to "volunteer" their services to aid less fortunate persons. Several are of particular importance in serving the frail elderly. VISTA enabled persons of all ages to serve persons of all ages. RSVP (Retired Senior Volunteer Program) provided reimbursement of actual expenses to older persons who performed a variety of services. Many recruits to the "Senior Community Service Aide" programs, operated under provisions of the Older Americans Act, have and are serving the elderly in the community who need simple help in the home, grocery shopping, companionship, telephone reassurance and other homely but very important daily coping assistance.

The Senior Companion program is the newest of these volunteer initiatives specifically designed to enable low-income elderly persons to have a meaningful role in society and to help functionally impaired and isolated adults live independently in the community for as long as medically and socially feasible. An additional purpose of the program is to help enrich the lives of persons who, because of physical, mental, or emotional conditions, need to be in the protected environment of an institution.

Advocates of the Senior Companion program believe it could be a major segment of a comprehensive approach to developing public policy and program for the frail elderly. Service as Senior Companions can forestall frailty for the volunteers by providing a meaningful role. Their role as a "significant other" could complement the work of the natural network of help, the family and formal service systems.

FORMAL SOCIAL SUPPORT SYSTEMS

Perhaps the term "formal social support systems" is too ambitious a description for a chapter which intends to describe those primarily non-health supportive services and living arrangements for the frail elderly which exist to a greater or lesser extent in every part of the United States today.

These programs are carried out in the government and in the private sectors -- both voluntary and proprietary. Programs in the private sector are being financed increasingly with tax dollars. Because this study is an effort to develop national "public" policy, the emphasis here, as throughout the report, will be on the role of the Federal government. At the same time, it must be acknowledged - without attempting to deal with its complexities - that the impact on voluntaryness by the infusion of government funds in areas which have traditionally belonged to philanthropy is a serious matter of concern.

This section will attempt to describe the scope, nature and trends of social supports for the frail elderly in order to assist policy-makers in contrasting and evaluating these programs with those based on a health approach to long-term care policy development.

It is important to note basic differences between health and social models. Health care is essentially dependency - creating because its complicated technologies require a great deal of decision-making by the technicians, primarily the physician as the manager of health care. The culture of health is costly and a major way to limit its cost is to avoid its use except for purely medical care.

What many believe to be the core of social work practice is one-to-one aid modeled after the caring, nurturing and coping roles of the family itself. In the social casework model conceived for the FCA services, every attempt is to be made to strengthen existing and available care within the family, only turning to the development of family-like supports when the real thing is not available or cannot do the whole job.

Although there has been a major increase in the last 10 years in Federal monies for social services for the elderly, both through age-integrated programs made possible by Title XX of the Social Security Act and age-segregated programs of the Older Americans Act, there is still some hesitation about just how far government should get involved in functions which many citizens believe to be the province of the family or at least of voluntary almsgiving and service.

Certainly, the national income strategy is based on the belief that, with enough money and a means of paying major medical bills, older persons will not need social services or social workers.

But the limitations of an income strategy are being increasingly appreciated and understood, particularly for the frail elderly and their families who, even with money, cannot cope with problems of daily living.

Age-Integrated Services

Title XX of the Social Security Act is the major Federal program for financing social services to vulnerable populations of all ages. Certain services tend to be specifically targeted to the aging population. These include day care and foster care for adults; home-delivered and congregate meals; home management, homemaker and chore services; protective services for adults and group activity centers for the aging. For the quarter ending June 1976, 265,602 aged recipients received one or more services.

The Federal government began substantial involvement in the financing of social services with the 1956 Social Security amendments. Lotis Rhodes, writing in Public Welfare; provides a useful historical perspective:

> The policy shift toward in-kind service as reflected in successive amendments to the Social Security Act from 1956 through 1975 - excepting those of 1972 - had little immediate and direct impact on service delivery to the elderly. However, the latent significance was twofold - and of conflicting nature. First, the actions established the concept of in-kind service and the resultant programs as an integral component of the public assistance system. This

breakthrough eventually led to the development and implementation of programs designed especially for meeting the unique needs of the elderly.

Second, the rapidly rising Federal expenditure for social services under the 75-25 percent matching grant formula approved in 1962 resulted in a $2.5 billion ceiling being slapped on spending for such services ten years later, by an amendment to the General Revenue Sharing Act of 1972.

Protective Services

The mandate in Title XX for protective services for adults who are unable to protect their own interests and are, therefore, in danger of neglect, abuse or exploitation has stimulated virtually all States to establish adult protective services programs and around 20 States to enact new adult protective services legislation. Workers in these programs are crowding every conference or training session which offers knowledge in skills to work with this multi-problem population. Because this population is quite likely to contain many of the elderly whom the FCA considers "frail", the role and status of protective services must be considered in developing national policy for the frail elderly and for long-term care.

The practice of protective services is not new. Under the direction of such leaders as Margaret Blenkner at the Benjamin Rose Institute, Gertrude Hall and Geneva Mathiasen at the National Council on the Aging and James Burr of HEW, the number of research projects, conferences, articles and books on protective services rose dramatically in the 1960s.

The surge of protective services as a result of the 1974 amendments is still being measured. For instance, in 1976 34 States had established protective services for adults. Information recently provided by HEW's Administration for Public Services indicates that all but three States now have a service under Title XX which can be identified as "protective services". Of the three, Colorado does have a service entitled "assessment of need for protective services" and Delaware has a public guardian who is a social worker. Only Wyoming does not offer anything which could be interpreted as a protective service.

The majority of the States that have supportive services included in their protective services program, provide these without regard to income at least in the short-term. Under Title XX, Federal aid is available without regard to income for services directed at the goal of preventing or remedying neglect, abuse or exploitation of children and adults unable to protect their own interests. The cluster of services provided by 33 States are health-related services, legal services, provision of alternate living arrangements, counseling and homemaker/chore services. They are provided both directly by State agency personnel and by public and private purchase-of-service providers.

According to the most current available data, adult protective services were provided to 133,408 primary recipients at a cost of $14,816,731.

In addition to Title XX, the Federal government also provides social services of help to the frail elderly through programs serving all ages administered through the Community Services Administration (formerly the Office of Economic Opportunity), legal services from the Legal Services Corporation, and community-based mental health care through the Community Mental Health Center program. Eligible veterans can receive a variety of aid from the VA.

A useful listing of Federal and federally-supported benefit programs and services can be found in the "Handbook of Federal Program Benefiting Older Americans" which is an appendix to the study of "The Interrelationships of Benefit Programs for the Elderly" of the Federal Council on the Aging (1975, p. 31, 32).

Age-Segregated Services for the Elderly

Dissatisfaction with the amount of support and interest from the voluntary sector and with government programs designed to serve all ages were major factors in the passage of the Older Americans Act in 1965. The Act established the

Administration on Aging as the Federal focal point and advocate for concerns of the Nation's older persons, designed to foster coordination and increased commitment of Federal resources to the field of aging. States were assisted in setting up similar focal points for aging concerns. Subsequent amendments provided Federal aid in establishing area agencies on aging within each State.

A "national network on aging" is now in place, consisting -- at the end of fiscal year 1977 -- of 56 State agencies on aging and 556 area agencies on aging located in 612 planning and service area. There were also 1,047 nutrition agencies operating 9,166 sites providing both congregate and home-delivered meals and certain support services. About 15% of the meals served were delivered to homes of persons unable to attend congregate sites because of impairments of short or long term duration. Funds for nutrition programs in fiscal year 1976 totalled $225,000,000.

In addition to the nutrition and other services available through Title VII, of the Older Americans Act, additional services for the frail elderly were provided through Title III of the Act. These include information and referral, telephone reassurance, chore services, in-home services, escort services and legal and other counseling. Title III provided over $77 million for the purchase of services in fiscal year 1977 -- not all for the frail elderly.

There is no income test for services under provisions of the Older Americans Act, except that participant contributions -- especially for meals -- are encouraged.

The role of advocate for the elderly and catalyst of efforts to sensitize non-Older Americans Act programs at the national, State and local levels to serve the elderly has been a continuing activity of the "network". The frail elderly have benefited from the wide range of AoA research and demonstration projects which have provided the knowledge base for many of the issues being developed in this current project of the Federal Council on their behalf. Service programs of particular benefit to impaired older persons exist in many communities throughout the country because of AoA demonstration grants.

The Carter Administration and the new Commissioner on Aging are putting their own stamp on the AoA advocacy role.

What Commissioner Robert Benedict has described as an "access assistance system" has special relevance to frail older persons with their problems of coping with systems of help.

In testifying before the Select Education Subcommittee of the House Committee on Education and Labor on the reauthorization of the Older Americans Act on March 20, 1978, HEW Secretary Califano asked Congress to add language to Title I of the Older Americans Act clearly calling upon all levels of government to help eliminate the remaining social barriers facing the elderly, and calling on State government to begin developing new systems of personal advocacy to protect the rights of older people. Under this proposal, the States would be asked, for example, to help train citizens to act as volunteer guardians and "representative payees" for elderly persons -- persons to help the elderly manage their affairs. States would also train and assist professionals, volunteers, and family members who work with older people each day in preparing such things as tax relief forms, Social Security applications and wills.

The 1978 legislative year saw the consolidation of certain of the service titles in the Older Americans Act to enable more efficient administration and more sensitivity to locally-determined priorities. There were also amendments to provide more attention to the frail elderly through special projects in comprehensive community long-term care.

In addtion to the Older Americans Act, the Senior Opportunities and Services (SOS) program established by the Economic Opportunity Act aids the frail elderly through various advocacy efforts and such help as employment opportunities for service to the frail by well -- but poor -- older persons.

Systematizing Services for the Elderly

While a social services strategy is being advocated as an equal partner to a health approach to long-term care of the frail elderly, the problems of inadequacy, poor delivery mechanisms and confusing philosophies and policies in the social service field must be acknowledged.

For instance, there is increasing conflict among advocates of the Older Americans Act whether to give priority to all the elderly or to poor, minority and impaired older persons. Another dilemma is the very philosophy behind the enactment of the Older Americans Act, namely, that the elderly do not get their fair share when they are "mainstreamed" with other ages. When HEW Secretary Califano testified in the House on the 1978 amendments to the Act, he advised deferring any substantive changes in the Act while working on some of these problems. He said:

> Over the past two decades, Federal, State and local agencies have rapidly expanded these programs to serve older people. But our compassion has too often exceeded our understanding. We have created a virtual maze which is often incomprehensible to the older people we are supposed to serve. Now we must take the time to re-examine carefully the organization and delivery of our services if they are to meet the pressing needs of the next decade.

In testifying before the House Select Committee on Aging at a hearing on oversight of Title XX on October 27, 1977, Nelson Cruikshank, Chairman of the Federal Council on the Aging, offered a conceptual framework for more effective administration of social services. He said he would ask the Council to develop recommendations for rationalizing at least the two major Federal social services programs for the elderly.

> I believe it is important to continue serving the elderly through both all-ages and aged-only programs. Both the Title XX agencies and State and area agencies on aging have planning and advocacy functions which are important for the elderly. There are many services, usually individually-determined and individually-delivered, which are needed by certain persons at all age levels and these might more appropriately be the responsibility of the public multi-generational casework agency. The protective services which are one of the most important Title XX programs for the elderly is one example. Many group services are unique to the needs and role of the older person and might more appropriately be lodged and financed on an ongoing -- not a demonstration and start-up -- basis in the Older Americans Act. There should not have to be a means test -- even if you call it "group eligibility" -- so an older person can attend a senior center. But neither

should older people be discouraged from paying for their own meal in a senior center so they can be full and independent partners is a "senior service" program.

Interface Between Federal Income Maintenance and Social Service Programs

The federalization of Old Age Assistance, which took place with the establishment of the Supplemental Security Income program in 1972, also furthered the goal of separating the administration of income-maintenance benefits from the delivery of social services. The policy shift had been started several years earlier with the intent of simplifying and making more equitable the administration of cash-benefit programs with the understanding that not all poor people needed services. The cash payments were supposed to enable most poor persons to cope. For those persons who did need some individual and person one-to-one help from a skilled person, the delivery of social services would be accomplished without the stigma of making a determination for cash benefits.

There were problems with this reform even when the separation of income-maintenance and social services merely meant dealing with two different units of a single local public welfare department. The need for social services was often identified during the application for income assistance. It was a built-in case-finding system especially for the frail elderly with their need for both income and services. When clients must deal with a Federal agency, namely, the Social Security Administration for SSI, and the local public social services agency for social services, the difficulty of frail older persons establishing a linkage to needed social services is compounded.

HEW's Social Security Administration and its Office of Human Development Services, the two Federal agencies which administer SSI and Title XX, are working at the national level to improve linkages and referrals between the Social Security District offices and local social services agencies. A joint work group composed of representatives of these two agencies is developing policy guidance, instructions and training efforts for SSA and Title XX staff. The Administration on Aging is also working with SSA on similar efforts of linkage.

Another problem area in the implementation of this nation's income policies for the elderly also bears closer examination and the development of not "just some working agreement" but possibly new legislation. The matter and manner of determining "representative payees" for SSI and retirement benefit recipients who cannot manage their own funds are problems which the Social Security Administration has limited capacity to handle. Especially for the frail elderly, the SSA handbook instructions are inadequate:

> Where it appears that the interest of a beneficiary would be served thereby, the Social Security Act provides that payment may be made for his use and benefit to a relative or some other person, regardless of the legal competency or incompetency of the beneficiary.

Dissatisfaction in regard to representative payee determination was expressed in 1964 by then Commissioner of Social Security Robert Ball:

> A quite serious problem in our program is the lack throughout the country of adequate community resources -- health, welfare and related services -- to help us in our task, to make more adequate determinations of capacity to manage, to find someone to act for beneficiaries who have no one with whom they have a meaningful relationship, and to afford at least some minimal protection to incapable beneficiaries living in situations which appear to be hazardous to them. There is urgent need for community services to which we can turn in situations like these. Our own service is incomplete without them.

Mr. Ball characterized phenomenon such as frequent changes of address as a danger signal. Upon investigation, it would often be found that this was indicative of a loss of capacity to manage. Current practice as to the determination of a representative payee varies. A number of SSA district offices frequently look to the local public social services department not only to make the initial evaluation upon which the SSA decision is made as to designation but also to maintain some kind of continuing supervision. Many and probably most SSA offices depend primarily on a determination of competency through medical or legal findings of incapability.

Regan and Springer, in the report of the Senate Special Committee on Aging on protective services described on pp. 87-91, express dissatisfaction with SSA procedures (and those of other Federal agencies as well) for determining substitute payees. They write:

> The entire system of substitutes is open to attack on constitutional grounds. The most telling point is failure of agencies to provide even minimal notice and a hearing on the issue of competency...The criteria to name a substitute are too vague. The Social Security Administration's concern for the best interests of the beneficiary is completely lacking in standards...The system of paying substitutes should not be discarded, even though it needs reform...The system might serve more effectively if it were part of other comparable State- or State-appointed guardianship arrangements, especially when the State provides a public guardian.

The FCA seriously considered recommending the Social Security Administration as the locus for its proposed set of services for the frail elderly because of SSA's national geographic coverage and linkages to virtually every older American through administering the trust fund programs and the Supplemental Security Income program. This approach was discarded when SSA acquired responsibility for administration of Aid to Families with Dependent Children and because it was felt that FCA's case assessment and management proposals should be more closely linked to community-based social services.

However, it could well be that the problem SSA faces with older persons who cannot manage their benefit payments might be one means whereby older persons could be identified as potential clients for case assessment and management. If the attainment of a certain age criteria for receiving the FCA proposed services were to be utilized, it might be possible for SSA to notify recipients automatically on their 75th or 80th birthday of the availability of this program rather than wait for some manifestation of difficulty in managing payments. And just as these FCA casework services might be located in the agency assigned responsibility for protective services by law so too might the determination of representative payees be linked to the community's formal procedures of determining the competency of frail adults.

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Supportive Living Arrangements

Assisted independent group living arrangements must be included in identifying the formal social supports which the Federal Government provides and which should be considered as part of public policy for the frail elderly.

Supervised living arrangements for those older persons whose mental, physical and social needs are such that they cannot manage in their own homes or those of relatives and do not need medical supervision, have perhaps the longest history in American public policy and programs for the frail elderly. The in-kind and "indoor" aid of almshouses was based on the Elizabethan Poor Law of 1601 which became a model law for this new nation.

Well before the outbreak of the American Revolution, all the leading coastal cities had erected almshouses (Coll, 1977). As originally conceived, these facilities were designed to provide decent, albeit modest, long-term care for indigent persons who were aged, chronically ill, or physically handicapped. Medical treatment was also provided for poor persons of all ages in need of but unable to afford private physicans.

Almshouses and county "poor homes" have long since ceased to exist but the need for a supportive non-medical living arrangement for frail older persons remains. A recent study of what is called "domiciliary care" in New York State* described the variety of terms used by the New York State Department of Social Services according to the size of the facility, the nature of ownership, and supervising agency.

Foster home care

Private homes in the community which provide for the care of a single adult. These homes are under the supervision of local social service departments but are not licensed.

Private proprietary homes for adults

Facilities operated for compensation and profit for the purpose of providing care to two or more adults, who require the services of attendants, but not medical or nursing care.

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*Community Research Applications, Inc. 1978

Family-type proprietary homes

Similar to private proprietary homes except they house at least two but no more than four residents. Licensed by the State Department of Social Services but inspection and supervision is from the county departments of social services.

Homes for the aged

Non-profit facilities which provide the same services as private proprietary homes for adults. Also supervised by the State Department of Social Services.

Residences for adults

Any facility other than a nursing home, convalescent home, home for adults, homes for the aged or aged care accommodation which holds itself out as providing living quarters, central dining and housekeeping services for adult persons who because of age or disability require a lodging, board and housekeeping service on a continuing basis. Must be approved by the Department of Social Services.

The New York State Department of Mental Hygiene has a separate system and terminology for its community living programs.

Family care homes

Private residences approved by an institution of the Department of Mental Hygiene as providing a healthful and safe family setting for no more than six persons with supervision from the institution's family care program.

Community residences

"Half-way houses" and "supportive living facilities" prepare a patient for independent living. A "supervised living arrangement" provides a long-term residence to persons unlikely to live more independently. Responsible supervisory staff is provided onsite 24-hours a day. Community residences are licensed and supervised by the Department of Mental Hygiene and may not exceed 24 beds.

New York is one of 32 States in which the SSI recipients residing in domiciliary facilities receive a State supplement to SSI in order to finance such care. It is estimated that some half million elderly persons are residing in adult care homes.

There have been abuses in these homes which the Keys amendment* to the Social Security Act attempts to stop. This amendment requires States to establish and enforce standards for non-medical residential facilities where "significant numbers" of SSI recipients reside or are "likely" to reside. If the States or facilities are not complying with the law, the Keys amendment requires reduction of benefits to the SSI recipients.

This reform measure was to become effective later this year but an important flaw has been identified which would penalize the individual SSI recipient by reducing benefits because of inabilities of State governments to develop necessary standards. Legislation has been introduced in this session of Congress which would delay the effective date of the Keys amendment in order to give both HEW and the States more time to develop the necessary paperwork procedures to curb the growing abuses in this burgeoning mode of care which is being used primarily for the mentally frail.

Enlarging Concept of Federal Housing Assistance

For many years, through formal and informal arrangements, it has been agreed at the Federal level that HEW and its programs would take care of the social service needs, if any, of residents of housing financed in one way or another by programs of the Department of Housing and Urban Development. It was believed that social and other "soft" services should not be part of the financing of building management costs.

With the aging of the population in publicly-financed housing and their need for certain supportive services in order to remain in an essentially residential situation, advocates for the elderly have been pushing for a change in Federal policy. As this session of Congress proceeds, both the House and the Senate are giving favorable consideration to legislation which would fund certain social services as part of the housing costs in public housing and projects built through loans for housing (Section 202) and housing assistance (Section 8).

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*Keys amendment was passed in 1976 as P.L. 94-566; amendment effective October 1, 1977.

Testifying before the House Select Committee on Aging in March 1977, Monsignor Charles Fahey, in his role as President of the American Association of Homes for the Aging, urged public housing policy which would be more realistic in regard to the social needs of those who live in federally-assisted housing projects.

> The single social change we could make affecting the lives of the elderly, that would promote the greatest social benefit for the least number of dollars would be to take all the federally-assisted housing, whether public housing or 202 or 236, and build into the basic financing mechanisms-- the operational financing mechanism--a certain floor of soft management services, and recognize this as an integral part of the subsidy, an integral part of the rent. I am not talking about all social services but I am talking about certain fundamental, soft management services: the ability to know the person in the facility, the ability to create a positive interaction among the people in the facility, the ability of the facility to create linkages with the community and serve as advocate for those individuals to get community services of whatever sort, certain nutritional counseling services, and certain public health type services.

Interface Between Health and Social Long-Term Care

This report has not tried to describe the range of health supports which can and should be provided by the "health care system" -- if there is such an entity anymore than there is a "social support system." What it has tried to show is that there are in existence a number of policies and programs which provide for a range of social supports for frail adults -- both the old-old and the non-old with chronic care needs. The diagnosis and prescription for some of these supports comes through the medical model but the need for many of them can be made by practitioners who do not have to be physicians in order to know that a frail person cannot reside in her own home without certain help for taking care of herself and/or her home.

"Home care" stands at the interface of the family and non-family systems of care for frail persons (Little, 1976). The ability of families to provide this care is as related to economic, housing and social services policy as it is to health policy. While it sounds very desirable, achieving administrative simplicity such as proposed by Trager (1977) might not really solve our need for a total perspective on long-term care. She writes:

> The best possibility of success for community care systems will be achieved when they are integrated into a single national funding system which emphasizes entitlement to services to fit need and which encourages easy movement between the various components -- those of prevention, preventive intervention, community care, ambulatory treatment and institutional care in a rational continuum.

Certainly some integration of programs can and should be considered. Congressional Budget Office proposals for combining long-term care aspects of Title XIX (Medicaid) and Title XX (Social Services) need to be assessed. Many of the home-delivered services provided through these programs are of the same type. The funding source is often determined by whether the particular State has reached its ceiling on Title XX. If it has, Title XIX, which does not have a cap is utilized. There have been a number of useful demonstration projects such as Triage in Connecticut and in Monroe County, New York, which have used waivers in Federal programs in order to achieve coordination of care in the community. Their findings should be studied.

Because of national income policies, many older people can pay for their own services if they and their families can have some assistance around brokering. Trying to finance some of these needs through a social insurance mechanism would be costly and, furthermore, it would seem that the nation is becoming reluctant to expand use of the social insurance system. Americans seem willing to utilize this system of financing for a new national health care arrangement but it is highly unlikely that they will be willing to include any but medical-related aspects of long-term care in a new national health care plan. The high costs of providing long-term care through the health system have already been described in this FCA report and a single system of community long-term care is very likely to be medically dominated.

The proposals of the Federal Council on the Aging for universal entitlement to case assessment and management are an attempt to provide psycho-social support and brokering for a frail individual through a personal agent rather than primarily through an agency. This will not solve the national long-term care dilemma either. But the Council believes it is a good base upon which to determine the best approaches to putting in place the skilled services and special facilities such as day care which are needed elements of a continuum of health and social care for frail adults outside a medical facility.

MOVEMENT FOR CHANGE

BECAUSE THE SOCIAL SUPPORT program being advocated by the Council must be coordinated with other relevant initiatives for the frail elderly, it is important to know the current public policy context within which decisions for this vulnerable population will be made.

Looking at the existing situation of overlap and gap, it is clear that there are dissatisfactions and differences of opinion on the part of those handling the programs and those receiving -- or not receiving -- the services.

Policy questions being widely raised and faced include:

1. What should be the extent of familial responsibility for its frail adult members?
2. How should public policies enhance and supplement the care of family, friends, philanthropy and business for frail adults?
3. Should the Federal government bring about the establishment of a long-term care system as a separate entity from health and social service systems?
4. Which health-related aspects of long-term care should be financed through a national health plan?
5. Which social service aspects of long-term care should be part of health care, which should be included in aged-only social services, and which should be available through an age-integrated social services system?
6. How can continuous and effective efforts to improve long-term health care facilities be assured?
7. Which mental problems of the elderly should be treated through psychotherapeutic treatment, which through a medical regime and which through psychosocial means?

8. Should federally-subsidized housing give priority to frail persons with the provision of certain supportive services as part of the housing subsidy?

9. To what extent should long-term care provided by the Veterans Administration be integrated with programs for persons not eligible for VA benefits?

10. Are there special problems caused by ethnicity or sex of the elderly which must be considered in developing national policy for long-term care?

11. Should eligibility for multidimensional assessment and case management be based on the attainment of a certain advanced age?

12. Which levels of government should have which responsibilities in caring for the frail elderly?

13. Should aids to older persons and their families for personal care services be provided in cash or in kind?

14. What are the manpower and training implications of trends in long-term care?

15. What pertinent research and demonstrations activities are required?

16. What care should be provided directly by government and what should be arranged through vendors? What should be provided as a social utility, what should be means-tested, and what should be available through a social insurance program?

17. How can care which is "least restrictive" of a person's rights to self-determination be provided by a benevolent government?

Government Studies and Views

The Congress has expressed concern about all of these questions in many ways. Hearings have been held, investigations have been undertaken and laws enacted over the past decade out of concern for the long-term care issue.

Examination of Congressionally-sponsored studies completed in 1977 underscores the increasing concern of national legislators. These studies include the following:

1. Returning the Mentally Disabled to the Community: Government Needs to Do More, General Accounting Office, January 7, 1977.

2. Catastrophic Health Insurance, Congressional Budget Office, January, 1977.

3. Long-Term Care for the Elderly and Disabled, Congressional Budget Office, February, 1977.

4. The Well-Being of Older People in Cleveland, Ohio General Accounting Office, April 19, 1977.

5. Home Health - The Need for a National Policy to Provide for the Elderly, General Accounting Office, December 30, 1977.

6. Study of Health Care for American Veterans, National Research Council of the National Academy of Sciences, June 7, 1977.

7. Protective Services for the Elderly, U.S. Senate Special Committee on Aging, July 1977.

8. Report of the Committee on Mental Health and Illness of the Elderly, U.S. Department of Health, Education, and Welfare, completed 1977, issued May 1978.

9. The Age Discrimination Study, U.S. Commission on Civil Rights, December 1977.

The data and observations in these reports are important in development of public policy initiatives for the frail elderly. The ensuing summaries focus on information of relevance to the concerns of the Federal Council, looking at some of many crosscutting issues which must be resolved in order to bring about a coordinated approach to long-term care.

STUDY 1 - General Accounting Office

RETURNING THE MENTALLY DISABLED TO THE COMMUNITY

In submitting this report on deinstitutionalization to the President of the Senate and the Speaker of the House of Representatives, Comptroller General Elmer B. Staats said that the General Accounting Office had made this review because the Congress had shown interest in helping States serve mentally disabled persons in communities, many problems had been reported in this area by the news media, and many Federal programs affect the mentally disabled.

The GAO considered both the mentally retarded and the mentally ill. While recent scientific advances are permitting more of the retarded to live longer, their numbers among the elderly do not yet come anywhere near the numbers of the elderly who have been institutionalized for what was considered to be mental illness. It is most appropriate to examine this GAO report for its implications for the frail elderly as it was the geriatric patient who was identified early in the movement for deinstitutionalization as being the major source of persons most likely to be inappropriately placed in mental hospitals.

Impetus for Deinstitutionalization

While the advent of tranquilizers in the 1960s and treatment philosophies and court decisions favoring community-based care and the "least restrictive alternative" contributed to the release of persons from public institutions, the financial savings to States provided by the passage of Medicare and Medicaid in 1965 were perhaps the most important factor.

Traditionally, State and local governments have been responsible for the care and treatment of mentally disabled persons. Patients transferred from State and county institutions to nursing homes and other community-based arrangements became eligible for these new Federal programs. The enactment of the supplemental Security Income program in 1972 furthered the discharge of the elderly into the community.

Data cited by the GAO from a survey completed in April 1974 by the National Center for Health Statistics, HEW, verifies a dramatic shift in population. While it was not possible to identify the number of mentally-disabled persons now in nursing homes who were released from public institutions, there has been a 48% increase in the number of nursing home residents with mental disabilities since 1969 -- going from 607,400 to 899,500. Of the latter number, the overwhelming majority, or 785,300, were 65 years of age or over. According to National Institute of Mental Health estimates, nursing homes provide the largest single place of care for the mentally ill.

It should be noted that in 1973-74, NCHS developed data from observations by nursing home personnel which indicated that of patients 65+, 6.6 percent of the nursing home population had a primary diagnosis of mental impairment including retardation, while some 17% evidenced mental impairment as a secondary or tertiary condition.

In 1963, when President Kennedy stated that it would be possible to reduce the population of public mental hospitals by 50 percent or more within a decade or two, about 504,600 persons were in such facilities. By June 30, 1974, the resident population of such facilities had been reduced by 57% to about 215,000 persons.

The GAO found that many mentally disturbed persons had been released from institutions and placed in decent housing in clean, safe neighborhoods and with structured in-house activities and outside programs such as work, education, recreation, and day activity center attendance. In such an environment, many mentally-disabled persons have become less dependent on either public support or other people for financial and daily-living needs and have learned to live normal or nearly normal lives.

However, the GAO observed that many other mentally-disabled persons enter, reenter, or remain in public institutions when they could be treated in the community. Others have been placed in substandard and crowded facilities in unsafe neighborhoods, or facilities that could not or did not provide needed services or assurance that they would receive needed services.

The GAO examined the particular responsibilities of the Department of Housing and Urban Development regarding the mentally disabled and found little enforcement of the provisions in the Housing and Community Development Act that communities consider the needs of the lower income, mentally disabled in their housing assistance plan. The Secretary of Labor had not informed the Department staff of their responsibilities in helping accomplish deinstitutionalization through job training and placement programs.

The Role of HEW in Deinstitutionalization

The GAO study began by describing the approach of the Department of Health, Education, and Welfare to deinstitutionalization as "disorganized". The several programs within HEW with relevant responsibilities were then analyzed.

Community Mental Health Centers and Clinics

- Increased services available from community mental health centers and clinics have not always reduced unnecessary admissions to mental hospitals or provided services to people released from mental hospitals.

- The mental health centers program has developed separately from the public mental hospital system, making integration of the two difficult.

- Allocations for mental hospitals still dominate most State mental health budgets, and restrictions and other problems have prevented the use of other funds for the mentally ill.

- Declining Federal funding for centers has caused several communities to avoid the program.

Medicaid

- Lacking alternatives, local programs use money provided by medicaid to place the mentally disabled in nursing homes, many of which are not staffed or prepared to meet the special needs of the mentally disabled or are not the best setting for persons so placed. (Subsequent regulations require an active treatment program if mentally-disabled patients constitute 50% or more of the institution's populations.)

- People were also placed in nursing homes or elsewhere without any release plans, with plans that did not identify all services needed, or without adequate provisions for follow-up services.

Medicare

- Medicare provides insurance for only limited outpatient care for the mentally ill. Because of this, many people may be placed unnecessarily in mental hospitals.

Supplemental Security Income

- Although SSI has helped mentally-disabled persons return to communities, some have been placed in substandard facilities, placed without provision for support services, or placed inappropriately.
- Legislation enacted in 1976 eliminated many previous reductions in SSI for mentally-disabled recipients in community residential facilities operated or assisted by public agencies.

Social Services

The major source of Federal funds to States for social service is under provisions of the Social Security Act administered by HEW's Administration for Public Services. Until October 1975, Title IV of that Act was available primarily for services that would help people obtain employment but it also included services to aid the mentally disabled in returning to communities from institutions and to prevent inappropriate placement where possible. Social services under Title VI were intended for the aged, blind and disabled who were former, current, or potential recipients of SSI to help them attain or retain capability for self-support and self-care.

In October 1975, a new Title XX of the Social Security Act (Social Services to Individuals and Families) replaced the previous titles.

Because Title XX became effective after the GAO had completed its study fieldwork, the report does not assess the impact of the new legislation on deinstitutionalization. It does note that HEW's regulations for Title XX may be weaker than the regulations for its predecessor program. States must make at least three services available to SSI recipients and provide at least one service for each of the five program goals of Title XX.

By requiring States to make at least three services available to disabled SSI recipients, the program should help make sure that mentally-disabled persons released from institutions, who receive SSI after release, receive at least some services.

On the other hand, GAO notes, States are no longer required to provide services according to service plans responsive to individual needs. Therefore, services provided by the States to mentally-disabled persons may not be the services they need the most to help them remain in the community.

State social service agencies are apparently not taking responsibility for making sure that foster or other community placements they make are appropriate to individual needs. Service responsibilities of social service agencies for mentally-disabled persons being released from institutions who are eligible for social services, but who are not SSI recipients, are not clear according to GAO.

Recommendations

Out of the many recommendations developed by the General Accounting Office, the following were selected for their relevancy to the frail elderly.

To the Congress

The Congress should consider, GAO said:

o Designating a committee in each House with responsibility for monitoring all Federal efforts to help place the mentally disabled in the community so that Federal agencies work together and support State efforts to serve the mentally disabled.

- Amending the Social Security Act to increase outpatient mental health services available under Medicare.
- Consolidating the funds earmarked for mental health under the special health revenue-sharing and the community mental health center programs into a formula grant to State mental health agencies.

To the Office of Management and Budget

At least 135 Federal programs -- administered by 11 major departments and agencies -- affect the mentally ill or mentally retarded, therefore, the Director of OMB should:

- Instruct Federal agencies to develop and help implement deinstitutionalization.
- See that the responsibilities and specific actions to be taken by Federal agencies are clearly defined.
- Direct Federal regional councils to mobilize, coordinate, and evaluate Federal work affecting this goal throughout the country.

To the Department of Health, Education, and Welfare

The Secretary of HEW should:

- Define responsibilities of and actions to be taken by HEW units.
- Designate an agency or official responsible for coordinating this work.
- Determine how to make sure that State and local agencies administering HEW-supported programs develop and implement effective case-management systems for people being released from public institutions.
- Evaluate the need and desirability of providing incentives for care for the mentally disabled other than in intermediate care facilities.
- Determine a clear and consistent Federal role in mental health and retardation programs and make recommendations to the Congress.

To the Departments of Labor and Housing and Urban Development

The Secretaries should each make community care for the mentally disabled a departmental objective and improve existing programs.

Agency Comments

Prior to the final issuance of this GAO deinstitutionalization report on January 7, 1977, the various Federal agencies whose responsibilities had been critiqued were asked their views on the GAO draft.

Labor and HUD generally agreed with the recommendations and outlined several actions they have taken, were taking, or planned to take to help return the mentally disabled to the community. HEW does not specifically comment on the recommendations, but said that it would study them and develop a plan for implementing those it concurred in.

The Office of Management and Budget disagreed with the recommendations made to it, arguing that they were unwarranted and would unjustifiably interfere with State and local responsibilities.

STUDY 2 - Congressional Budget Office

CATASTROPHIC HEALTH INSURANCE

This report was produced to assist the Congress in determining the expansion of the Federal role in financing health care services. Congressional Budget Office Director, Alice M. Rivlin explains that expansion could take the form of a national health insurance plan covering all persons for a broad range of services, or it could involve selective extensions of coverage by type of risk insured or by population group protected.

One widely discussed alternative for selectively extended coverage is catastrophic health insurance. This Budget Issue Paper examines the frequency and origins of "catastrophic" expenses; the extent to which they are currently met through public programs and private insurance; and various proposals for insuring catastrophic costs. As is customary policy and practice of the CBO, this paper included no recommendations. However, an implicit view of the agency is conveyed by exclusion of long-term care from consideration in this report and as a component of alternative policy proposals for catastrophic insurance. Instead, CBO produced a separate companion report entitled Long-Term Care for the Elderly and Disabled. (See p. 72,73)

Whether "catastrophe' is defined as a large absolute expenditure or an expenditure which is large relative to an individual's income, the CBO makes clear that at the present time, the most significant catastrophic expense problem is long-term care. In fiscal year 1978, an estimated 1.3 million persons will be residents of nursing homes for six months or longer, at an aggregate cost of about $14.7 billion. Almost 55 percent of that cost, or $8 billion, will be paid directly by consumers. As the major third-party reimbursement plan, public or private that provides substantial coverage for long-term nursing home care, Medicaid pays the rest of the bill except for limited aid available through Medicare.

The reasons for considering long-term care separately are clearly set forth by CBO:

> Long-term nursing home coverage has been excluded in each CBO alternative plan, despite the fact that nursing home care is the major cause of catastrophic expenses among the aged. The financing of long-term care poses many complex social and administrative problems not involved in the financing of other types of health care. Some of these problems stem from the peculiar nature of the service, which is often more custodial or residential than strictly medical. Thus, judgement must be made about the extent to which a health insurance benefit should subsidize the care, and to what extent other forms of housing, income assistance, or social services are more appropriate.
>
> Additional problems arise from the nature of the population group that required long-term care.
>
> -- 75% of persons in nursing homes are over the age of 75.
>
> -- About 40% are more than 85 years old.
>
> -- Many have no close family members and are not competent to manage their own affairs.

-- Close supervision is necessary to assure that funds are not misused and that the most suitable level of care is provided.

Because the elderly share other catastrophic health costs with the general population connected with their acute health care needs and because the issue of financing long-term care should be considered concurrently with proposals for financing these other catastrophic needs, it is useful to describe here the three catastrophic protection plans that reflect the major types of approaches that have been proposed. A fourth alternative, a uniform national program to address the specific problems of both low- and middle-income families, was also presented by CBO to illustrate the extremely high costs of such a program.

Alternative One: A Traditional Insurance Plan

An insurance plan designed to operate as a supplement to basic private insurance and Medicare removes all limits on Medicare hospital coverage and coinsurance and places a $250 limit on cost-sharing for non-hospital services. Medicaid would remain unchanged. Net new cost to Federal Government, $12-$13 billion FY '78.

Alternative Two: An Income-Related Plan With Fixed Maximum Liability

Covers all out-of-pocket expenses except those for long-term care in excess of a designated percent of a family's gross income. Relatively complex and expensive to administer because of income-tested benefits. Benefits proportional and targeted to meet greatest need. Difficult to integrate with basic insurance. Financed through Federal general tax revenues. Net new cost to Federal government $14.9 billion FY '78.

Alternative Three: A Mixed Traditional and Income-Related Plan

Federalized Medicaid program providing total expenses for low-income families and the exceptionally high expenses of Medicare beneficiaries. Extension of Medicare same as alternative #1. Benefits targetted to greatest need. Compatible with basic insurance. Reasonably uncomplicated to administer because income-testing is minimized. Net new cost to Federal government, $24 billion FY'79.

Alternative Four: A Uniform and Universal Plan

HEW "Mega" proposal in 1973 designed to deal with the specific catastrophic expense problems of both low-income and middle-income families through a single program. Addresses all major catastrophic cost problems except long-term care. Would actually be an expensive comprehensive national health insurance plan. Net new cost to Federal government, $79 billion FY '78.

STUDY 3 - Congressional Budget Office

LONG-TERM CARE FOR THE ELDERLY AND DISABLED

This long-term care budget paper presents three options for Federal aid to individuals, communities and States in caring for the elderly and disabled, which should be considered along with the three CBO options for catastrophic health insurance. (See Study 2 page 71)

Background

Long-term care, as defined in this CBO paper, refers to services provided over an extended period of time to persons with chronic physical disease or disability. The long-term care needs of the mentally retarded and mentally ill -- a group almost equal in magnitude to the physically disabled -- were not included. The report explains why:

> Long-term care of the mentally ill and retarded in-involves considerations similar to those involved in the care of the physically disabled, including the lifetime nature of treatment and the appropriateness of institutional versus noninstitutional treatment. However, many of the services required by the mentally ill and retarded are different and, historically, have been administered through separate delivery systems by a separate class of professionals. The distinctions found between acute care, psychiatric care, and long-term care of the disabled will therefore be retained here, although they are made more for the sake of administrative simplicity than for conceptual purity.
>
> With the exclusion of the mentally ill and retarded, the group most likely to require long-term care as a result of physical disability is the elderly.

They have the highest incidence of chronic illness, disability, and functional impairment, although other individuals suffer from these on a less predictable basis.

Federal Program Options For Long-Term Care

The three general types of options presented by the CBO reflect different policy approaches with different budget impacts. The general approaches are:

A. Modification of Existing Program

Medicare would be modified to liberalize coverage of home health services while retaining the link to treatment of an injury or an acute illness. The liberalization might be accomplished by eliminating the requirement that patients be homebound and expanding the definition of skilled services to include nutritionist services and occupational therapy. Homemaker services under the supervision of a nurse could also be permitted after skilled services were no longer necessary.

An alternative to financing these medicare services would be to combine home health services of Part A (hospital benefits paid by a payroll tax) and Part B (non-hospital health services paid from general tax revenues and monthly premiums) into a new Part C. This would have no hospitalization requirement and no deductible, but would require a uniform $2 per visit co-payment for all covered services.

Medicaid could similarly be altered by requiring that all States provide at least the acute home health services covered under Medicare including the just mentioned proposal to eliminate the requirement that patients be homebound. Moreover, the CBO suggests mandating a minimum level of home-based services rather than leaving this to the states. These basic social services would be at a level to maintain a sick or incapacitated person at home if that were more economical than institutionalization. Counseling by medical social workers would be a covered service.

B. Long-Term Care Insurance

A social insurance program would provide universal coverage of long-term care for all aged and disabled persons without a means test. The services covered would include nursing home care, personal care homes, congregate housing, foster care, home health care, homemaker and social services, and adult day care. It would be financed principally by the Federal government, although the State could pay some portion of program costs.

Expands Medicare as in Option A; explicitly replaces the Federal/State Medicaid program. Includes co-payments designed to reduce financial incentives favoring institutional care over sheltered living or home care and to provide incentives for obtaining help from friends and relatives rather than through personal care and homemaker services. Low-income patients would receive a co-payment allowance which could be used either to pay the co-payments or be retained by the patient if alternatives to formal care are used.

C. Comprehensive Long-Term Grant

This option combines Medicaid long-term care funds and Title XX social services into a comprehensive long-term care grant financed 60 percent by the Federal government and 40 percent by the States. Option A changes in Medicare would be included. As a condition of receiving grants, States would establish long-term care centers; independent semi-public agencies responsible for identifying the aged and disabled in the area and assessing their needs, certifying providers, authorizing levels of care, and monitoring the quality of services. The centers would be the sole channel of Federal long-term care funds.

Because the entitlement program under Option B is expensive, Option C is offered as a possible way of unifying long-term care funds but controlling growth through appropriations. Like Option B, Option C would provide an administrative focus for long-term care services at the local level. It would eliminate the divisions between health and social services that are necessitated by current financing arrangements and establish a uniform set of services to be covered.

National-State and Community Responsibilities

A comment in the CBO analysis raises an issue which some believe is critical and yet has hardly been touched in the nationwide concern about long-term care; namely, the extent to which this nation wishes to "federalize" long-term caring for people.

A social insurance program (Option B) will, over time, accumulate a detailed set of uniform service criteria and detailed regulations to be applied nationally. Long-term care centers could become simply extensions of the Federal bureaucracy, with functions analogous to that of insurance carriers under Medicare. The existing patterns of care--the professionals, institutions, organizations, and administrative agencies--vary greatly across the country and even within the same city or county. It will be difficult to capture these variations with a detailed set of national regulations. Moreover, the level of understanding of what types of programs, organizations, and services will be most effective and efficient is very limited. The diversity of approaches to long-term care permitted under Option C might provide the data to show which approaches are most desirable.

Because there is very little organized long-term care at present, a comprehensive, organized system of long-term care services will be a fundamental change. Flexibility in this development is essential in order to learn from mistakes and to adapt to the problems brought about by changes. This flexibility is much easier to obtain in local programs, in which the ease of communication necessary to study problems and initiate changes in greater.

Financing of CBC Proposals

A CBO technical analysis paper entitled Long-Term Care: Actuarial Cost Estimates explores potential cost and demand for long-term care and estimates cost for Options A and B. (It will be recalled that Option C is based on a continuation and probably slower growth of monies already allocated for the two Federal programs which C amalgamates.) The following table provides an indication of the relative costs envisioned.

ESTIMATED TOTAL COST UNDER EXISTING PROGRAMS AND UNDER OPTIONS COMPARED TO ESTIMATED POTENTIAL DEMAND FOR SERVICES: BY FISCAL YEAR, DOLLARS IN BILLIONS

	1980	1982	1985
Potential Demand	32 - 47	42 - 60	60 - 87
Existing Federal Programs	7 - 8	9 - 10	15 - 17
Option A a/	8 - 9	11 - 14	18 - 28
Option B a/	20 - 23	29 - 36	47 - 73
Option C a/ b/	8 - 9	11 - 14	18 - 28

Study 4 - General Accounting Office

THE WELL-BEING OF OLDER PEOPLE IN CLEVELAND, OHIO

This is the first section of a two-part study undertaken by the General Accounting Office on the well-being of older people in Cleveland. The second report presented changes in the survey group over a one-year period. It identified what may have contributed to those changes and recommendations were made as to what can be done to improve older people's well-being.

The GAO undertook this study because of the concern of Congress that Federal programs and appropriations for the elderly should have substantive impact on their lives. Twenty-three Federal programs were examined along with the array of State, local, and private programs available in Cleveland.

The Cleveland survey group was composed of people 65 years of age and older who were not in institutions such as nursing homes. National statistics were used to assure that the sample was demographically representative and the results

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a/ Fiscal year 1979 is the first year of operation.

b/ Minimum cost. Maximum is the same as Option B.

were checked against a similar study undertaken by the Duke Center for the Study of Aging and Human Development in Durham, N.C. The major difference was in race, with the Cleveland and Durham samples both having at least three times more blacks represented than were included in nationwide figures.

The survey was carried out through use of a questionnaire developed by the OARS program (Older Americans Resources and Services) at Duke University through funding from the Administration on Aging and the Social and Rehabilitation Services of the Department of Health, Education, and Welfare. The "Multidimensional Functional Assessment" is an appendix to the GAO report. It contains questions about an older person's status in five areas of functioning: social, economic, mental, physical and activities of daily living.

Selected Major Findings

Family and Friends as a Resource

Home help services such as personal care, homemaking, meal preparation, continuous supervision and transportation were provided primarily by family and friends. Eighty-seven percent of the survey group indicated that a primary source of help was available in the event of sickness or disability. Children would be turned to first by 42%; spouse next by 27%; brother or sister was next at 10%; followed by other relative 9% and friend 8%.

GAO believes that the family and friends of other older people could be encouraged to provide similar services. Training for family and friends and financial incentives through the income tax system or direct payments are suggested. However, GAO cautions that any such effort should be structured to encourage and support the many family members or friends who are currently serving older people.

Location of Services

The GAO study team found that many low-income older people live in higher income neighborhoods while many agencies concentrate services in low-income neighborhoods.

Multiple services are available primarily in Cleveland public housing sites. However 9% of the sample, not living in public housing, needed multiple services but were not receiving them. Conversely, 27% of the study group who lived in public housing were unimpaired or only slightly impaired.

Many Older People Do Not Use Federal Programs

Seventy-seven percent of those in the sample who were eligible for food stamps were not receiving them. Supplemental Security Income (SSI) was not being received by 52% of the elderly eligibles and Medicaid was not being used by 29% of those who were eligible.

Older Persons Do Not See Benefits of Certain Programs

Most older people who could benefit from home help - personal care services expressed a need for them. Because older people are willing to express a need for such services, GAO believes such services may be successful if the older persons are merely aware that the services exist.

Of the economically impaired, only 52% expressed a need. Only 8% of those with a need for mental health services and 35% needing psychotropic drugs recognized their impairments. The GAO calls for special outreach efforts to reach these groups.

Assessment and Referral Services

Of those who were generally impaired or worse, 56% who received assessment and referral services also received four or more other types of service compared to only 40% of those who did not receive assessment and referral. Financial assistance and assessment and referral services came about evenly from family-friends and an agency.

STUDY 5 - General Accounting Office

HOME HEALTH - THE NEED FOR A BETTER NATIONAL POLICY

Upon the request of Congressman Claude Pepper, Chairman of the House Select Committee on Aging, the General Accounting Office undertook this study of the cost of providing home health care to the elderly including the value of services provided by family and friends, as compared with the cost of nursing home care. The report also discusses the estimated cost of certain proposed legislative changes for liberalizing home-health benefits under Medicare and the need for a national policy to better provide for the elderly where the services of families and friends are not available. Much of the data for this report was drawn from the GAO Cleveland study just described.

Population and Care Characteristics

- About 17% of persons 65 years of age and over are greatly or extremely impaired*; one-third are in institutions and the remainder are cared for at home primarily by family and friends with some assistance from unevenly available formal community services.
- Eighty-seven percent of institutionalized older persons are greatly or extremely impaired compared to 14% of those at home.
- Care provided to the greatly or extremely impaired at home is similar to institutional care.
- Greatly or extremely impaired people require more than nursing services to be maintained in their homes.
- Family and friends provide 50% of the services received by older persons at all impairment levels and over 70% of the services received by the greatly or extremely impaired.
- At all levels of impairment, the value of services provided by family and friends greatly exceeded the cost of services provided by public agencies at public expense.
- At the "greatly impaired" level where the breakeven point between the cost of home care and institutional care is reached, families and friends are providing about $287 per month in services for every $120 being spent by agencies.

Options for Liberalizing Home-Health Benefits

Medicare

The elimination of the limitation on the number of home health care visits, all other requirements being continued, would not be costly ($12.5 million) because few people presently exhaust such benefits.

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* For GAO definitions of impairment see pp. 28-29.

Removing the requirement that a beneficiary must need skilled nursing care, or physical or speech theraphy in order to receive a variety of additional services, including home health aides, occupational therapists and medical social workers, as well as coverage of medical appliances and supplies, would cost an estimated $1,250,000,000. ($938 million for part A and $312 million in part B) in fiscal year 1978.

This change would also affect the acute care orientation of Medicare.

Eliminating the requirement that a beneficiary be an inpatient for at least three consecutive days to receive home health benefits under part A would cost about $12.5 million in fiscal year 1978.

Elimination of the homebound requirement would expand benefits to a new category of patients and cost about $92.5 million in fiscal year 1978 if all other requirements remained unchanged.

Medicaid

The cost of adding home health care benefits under Medicaid as a required service should be minimal because 32 States and jurisdictions already offer this service to all aged, blind, and disabled categorically-needy individuals 21 years of age and older.

Homemakers

Congressman Pepper also asked the GAO to study the Federal cost impact of adding home health aide and homemaker services to Medicare and Medicaid. For Medicare, actuaries of the Social Security Administration said that assuming an individual is homebound, in need of skilled care and that the homemaker services are provided only while skilled care was required, additional homemaker services would cost $75 million in fiscal year 1978.

Selected Recommendations

HEW should:

- Develop a national policy consolidating home health activities for Congressional consideration.

  The GAO study states that, because HEW has had little success in developing an overall national policy on home health care, the Congress enacted legislation (H.R. 3) requiring the Secretary to submit a report by October 25, 1978 to the appropriate committees of the Congress analyzing, evaluating, and making recommendations for changes in regulations and legislation on all aspects (including availability, administration, reimbursement procedures and cost) of the delivery of home health and other in-home services authorized to be provided under titles XVII, XIX, and XX of the Social Security Act. The report is also to include an evaluation of the coordination of home health and in-home services provided under these titles.

  It is the view of the General Accounting Office that the HEW study should also consider the coordinating services provided under Titles III and VII of the Older Americans Act.

- Promote the establishment of a comprehensive single entry system by which individuals are assessed as to their needs prior to placement in a home health care program.

- Have intermediaries and carriers publicize the use of home health care and provide information concerning the availability of home health services to physicians and institutional providers.

  In GAO's report on Home Health Care Benefits under Medicare and Medicaid issued July 9, 1974, it was found that many physicians were unaware of the types of services which are provided by home health agencies. GAO believes this condition persists in 1977 despite the many efforts in the interim by HEW.

Congress should:

Consider focusing the jobs, created as part of any welfare reform legislation, on service to the sick and elderly who live alone and are without family support.

STUDY 6 - National Academy of Sciences

HEALTH CARE FOR AMERICAN VETERANS

Under provisions of the Veterans Health Care Expansion Act of 1973 (P.L. 93-82), the Congress directed the Veterans' Administration (VA) to contract with the National Academy of Sciences (NAS) to study the VA health-care system. The law specified that this undertaking should "...determine a basis for the optimum numbers and categories of such personnel and other resources needed to insure eligible veterans the provision of high quality care in all hospital, medical, domiciliary and nursing home facilities."

The importance and necessity of examining the role of the VA in relation to the frail elderly has already been indicated by data cited earlier in this FCA report, namely, that by the year 2000 almost 60% of the American male population of 7.1 million men 65 years of age and older will be veterans. They will comprise 25% of the surviving veteran population at the turn of the century if no new war occurs in the interim. (In 1970, only 8% of veterans were over 64 years old.) While not all these men will have service-connected disabilities, most will still be eligible for practically all VA health benefits once they attain age 65, depending on their economic situation, if they were a veteran of any war or of service after January 21, 1955 and have an honorable discharge.

Saul J. Farber, MD., Chairman of the Department of Medicine, New York University School of Medicine served as Chairman of the Committee on Health Care Resources in the VA which was established by the National Academy of Sciences to undertake the study. Dr. Farber described the study as the first comprehensive evaluation of a large health system in the United States. Resulting data from its examination of acute hospital care, psychiatric care, nursing home and domiciliary care provide an important perspective on present and future long-term care planning for all defined as "veterans". (Women veterans were not included in the study because of their small numbers.)

Selected Findings

- o All the major health-care services provided by the VA -- hospital care, long-term care, and outpatient care -- are provided mainly to veterans without service-connected disabilities. Most VA patients do not have health insurance and are disadvantaged medically and economically.

- o VA health-care expenditures are about 10% of total Federal health expenditures and are continuing to grow at a rate that is greater than the growth rate of national health expenditures because of the VAs emphasis on institutional services.

- o A high proportion of patients receiving inpatient care on the medical service are poor and elderly and suffer from a chronic illness. Forty-eight percent have an annual income below $5,000 and 54% receive compensation for a service-connected disability or a VA pension. In one of the surveys undertaken as part of the NAS study, it was estimated that 48% of the patients in acute-care medical beds were suitable for ambulatory care or in some form of extended care arrangement.

Extended-Care Facilities

The Veterans' Administration was not authorized to operate nursing homes until 1964. Public Law 88-450 also authorized the VA to contract with private or public nursing homes to care for VA patients who have recieved maximum hospital benefit, but require a convalescence of no more than six months. In fiscal year 1975, the average census of patients on VA contract in community nursing homes was 6,239.

Within facilities operated directly by the VA, 24% of all operating beds or 26,926 are in three kinds of extended-care facilities: 7,032 in 86 nursing homes, 9,584 in 56 intermediate-care units, and 10,310 in 18 domiciliaries. (Intermediate-care units in VA parlance are redesignated hospital wards where minimal medical supervision is required but more than is available in a skilled nursing home.)

The VA also provides a partial subsidy for the cost of caring for 4,123 veterans (on a daily census basis) in domiciliaries, nursing homes, and hospitals in 38 veterans homes operated by 31 States.

In addition to these long-term care programs, at the end of fiscal year 1975 the VA was providing a partial subsidy for the cost of caring for a daily census of 4,123 patients in State-operated veterans nursing homes and 5,849 in State-operated domiciliary-care units. The purchased or subsidized services involved 16,211 patients.

The NAS Committee found the overall quality of long-term health care directly provided by the VA to be acceptable -- superior to a great amount of the care provided outside the VA.

Domiciliary care originated in 1866, when the Congress established 11 National Homes for Disabled Volunteer Soldiers for veterans whose war injuries prevented them from earning a living. Admission criteria have changed over the years. The 18 units which are presently operating place emphasis on a therapeutic environment rather than just custodial care.

The mean age of veterans discharged from the domiciliary program according to a June 1973 study was 60; 90% were unmarried and 10% had living spouses; 28% had a current diagnosis other than alcoholism.

The study committee from the National Academy of Sciences described the program of the domiciliaries as being residential rather than rehabilitative and the social climate reflecting an institutional pattern of formal behavior, best described as benevolent paternalism. "The facilities provide austere homes for a disaffiliated, infirm population of men."

Psychiatric Care

The NAS group felt the figures cited above understated the amount of long-term care provided by the VA. They reaffirmed past VA studies indicating that 40 to 50 percent of VA psychiatric beds are being occupied by patients who do not require the resources that are found only in hospitals. The lack of available alternatives, the absence of family support, and the inadequate staffing of special support services persists and hampers efforts to relocate patients outside VA hospitals in more suitable settings.

About 55% of all patients with a psychiatric diagnosis were 45 years of age or older and were diagnosed as having either functional psychosis or organic brain syndrome. Only 29% were being treated for service-connected disabilities; 28.5% of VA psychiatric patients were married.

Recommendations

Among the many recommendations made in the study with particular relevance to the care of frail older veterans now and in the future were the following:

- The VA should attempt to merge its long-term care facilities with non-VA programs. Although its role in long-term care is likely to persist for a longer period of time than its role in delivering regular medical service, it should concentrate on improving its long-term care programs in ways that will facilitate linkages with community facilities.

- The VA should explore the possibility of enlarging the role of the States in providing long-term care to veterans.

- Inappropriately hospitalized psychiatric patients could be discharged through developing and implementing such alternatives as expansion of VA mental-health outpatient facilities and personnel, partial hospitalization, halfway houses, sheltered workshops, group homes and cooperative apartments. There should be greater collaboration and possible integration between VA services and community mental-health resources.

- All VA long-term care patients should get comprehensive dental care.

- The VA should improve its procedure for assessment of patient needs and use them for staffing, care planning, supervision, quality assurance and design of appropriate facilities. Existing instruments for measuring patients' requirements for nursing care should be utilized and refined continuously.

Response of the Veterans' Administration

The Veterans Health Care Expansion Act which mandated this study by the National Academy of Sciences also called upon the Administrator of the Veterans' Administration to report his views on the NAS findings and recommendations, any disagreements, and steps that would be taken to implement the findings and recommendations.

The VA did not concur in the NAS recommendation that its long-term care facilities be merged with non-VA programs, saying that this did not recognize that the most effective long-term care cannot be rendered apart from acute care. The VA said it now uses community resources and believes coordination of VA and non-VA programs is important when it is in the best interest of the veteran.

The VA concurred in the recommendation that the States' role in providing long-term care to veterans be enlarged and in the recommendation that alternatives to psychiatric inpatient care be pursued.

The National Acadamy of Science recommendation that all VA long-term patients should get comprehensive dental care was agreed to by VA.

P.L. 94-581 also directed the Chief Medical Director of the Veterans Administration to prepare a report on VA programs and plans for meeting the problems generated by the increasing numbers of aging veterans. The report entitled The Aging Veteran: Present and Future Medical Needs describes plans for adjusting the number of VA hospital, nursing homes, intermediate care and domiciliary beds; expanding alternatives to institutional care including provision of home health services; emphasizing education and training of health care personnel specializing in geriatrics; and emphasizing biomedical and health services research designed to ameliorate geriatric care.

The report concludes with the official VA view that it believes its plans for coping with the increasing number of aging veterans are comprehensive but flexible enough to meet changing needs as knowledge and technology develop.

> These projections have been made on the assumption that the present patterns of VA utilization will continue. Public funds now subsidize 91% of hospital care, 59% of physicians services, and 54% of nursing home care costs for persons over the age of 65 years. Since most national health insurance legislation proposed to date does not include the elimination of co-payments or significant changes in nursing home care coverage, it is possible that national health insurance may not have large immediate impact upon the veteran with limited resources who now seeks VA services.

STUDY 7 - Senate Special Committee on Aging

PROTECTIVE SERVICES FOR THE ELDERLY

This working paper on the status of protective services in the United States today was prepared for the Senate Special Committee on Aging by Professor John Regan of the University of Maryland Law School, and Georgia Springer, a staff attorney for the National Council of Senior Citizens' Legal Research and Services for the Elderly project. David Marlin, Director of the LRSE project, coordinated the preparation of the working paper.

In his preface to the report, Senator Frank Church, Chairman of the Special Committee on Aging, describes how the major responsibility for the provision of "protective services" -- help, sometimes with legal sanctions, needed by mentally and physically infirm elderly citizens to carry out activities of normal living. He goes on to say that there is a growing Federal involvement, not only in the means of payment directly for such services in several nationwide programs, but also in the development of an overall service network intended to help prevent the need for such intervention in the first place, or -- if infirmity has occurred -- providing assistance which may help prevent institutionalization.

The law in most States has authorized intervention in one of several ways:

Civil commitment to an institution.

Guardianship of the person which transfers control over personal decision making.

Guardianship (conservatorship) of the property which transfers control over one's property and financial affairs.

Protective services laws authorizing temporary intervention and protective placements.

The authors trace the involvement of government in the lives of the mentally disabled to English common law. As father of the country (_parens patriae_), the English king was responsible for the protection and care of the person and property of the mentally incapacitated. This paternalistic practice was brought to colonial America and is the father of today's various legal and social protective proceedings and services for the incapacitated. Recent court decisions have challenged the parens patriae power of the State. The Senate Special Committee on Aging report refers to what has come to be known as the principle of the "least restrictive alternative".

> If the State has the right to deprive a person of liberty by civil commitment for treatment or care, does it also have an obligation to provide care or treatment with the least necessary restrictions on that person's liberty and other civil rights?

The report sets forth the dilemma for the various disciplines, especially law and social work, in dealing with these evolving legal principles affecting the welfare of the frail elderly.

> Social workers proceed to deliver services at times against a client's wishes, without an understanding of potential violations of legal and constitutional rights of the clients or their own vulnerability. They do not invoke legal sanctions or use legal processes because the former are often inadequate, the latter often unavailable.
>
> Lawyers are often unavailable and/or incapable of working in a situation with unfamiliar psychiatric, social service, and medical complexities. Laws relating to intervention are unclear and rigid, providing an all or nothing approach so fashioned that disabled persons may lose all their civil rights when civil commitment or guardianship is imposed. A lesser, simple degree of intervention to place a person in a protective setting or to intervene on an emergency basis is frequently unavailable.

Model Laws

This report tries to bridge the gap between practice relating to "protective services" and the law by proposing model State legislation for:

An adult protective services act

Guardianship, conservatorship and power of
Attorney laws
A public guardian act.

An amendment is also proposed for State civil commitment statutes which establish criteria for involuntary admission of patients to mental hospitals. The proposal would prevent involuntary commitment if a less restrictive alternative form of care and treatment would be adequate for the person's needs, not whether such an alternative is actually available. It is also recommended that similar language be added to the legislation which authorizes State agencies or information services to conduct periodic review of patients already residing in mental hospitals, as well as to statutory provisions for judicial release of patients.

The enactment of all this proposed legislation is intended to be a program of services for the elderly to assist them to avoid institutionalization and a spectrum of alternative forms of legally authorized intervention in the elderly person's life calibrated to provide only the specific services necessary to meet immediate needs and avoid more drastic interference.

The model legislation has related features; some of which clarify existing programs and policies, others are innovative approaches using new knowledge about the elderly and the treatment of mental illness:

Protective Services

The (State agency responsible for community-based services to the elderly) shall develop a coordinated system of protective services, for elderly infirm and incapacitated persons with the person's consent or appropriate legal authority, in order to assist the person in performing the activities of daily living, and thereby maintain independent living arrangements and avoid hazardous living conditions. The Department may provide direct protective services or designate any public or private agency as a protective services agency. The services would be financed by the provider agency, which may in turn be reimbursed from Federal or State sources if such funding is available. A rigid means test should be avoided but persons who can afford to pay may consent to do so or the court may authorize payment.

It is intended that these protective services be only a specific portion of a broader program the purpose of which is to prevent or delay institutionalization of the elderly. The characteristics that distinguish protective services from these larger programs are:

1. Their target population is infirm, incapacitated, or protected persons.
2. The services are provided by a designated protective services agency.
3. Unless the elderly client consents to accept the services, the protective services agency may intervene only with court authorization.

Geriatric Evaluation Service (GES)

A team of medical, psychological, psychiatric, and social work professionals established by the (State agency responsible for community-based services to the elderly) for the purpose of conducting a comprehensive physical, mental, and social evaluation of an elderly person for whom a petition has been filed in a court for commitment to a mental hospital, appointment of a conservator or guardian, an emergency order for protective services, or an order for protective services, or an order for protective placement. The GES recommendations would be used by the courts in determining the appropriate setting for care and treatment and the degree of restriction on self-determination.

Public Guardian

Provides free or low-cost guardian and conservator services for persons having no able or willing friends or relatives within the jurisdiction of the court; and to those persons whose income or wealth is inadequate to provide the requisite compensation to a private guardian or conservator.

Four alternatives are provided for the location of the office of public guardian:

a. Each court of the State which has original jurisdiction in guardianship and conservatorship hearings.

b. Office of the Governor.

c. Within an agency of the executive branch of State government (State office on aging; the State department of social services; the State department of health and mental hygiene)

d. Within county government.

The Senate Special Committee on Aging working paper on protective services observes that despite the safeguards for curbing abuses of the intervention power, these proposed reforms accept the _parens patriae_ power of the State. It concludes that to shirk a duty to the disabled in the name of personal liberty, when the victim is, by definition, incapable of a rational decision, is grievously wrong because the liberty is no longer grounded on the ability to make a rational choice. "The paradoxical but inescapable conclusion is that a controlled and limited exercise of the _paren patriae_ power by the State is necessary if personal liberty is to be a reality and not a fiction."

STUDY 8 - HEW

COMMITTEE ON MENTAL HEALTH AND ILLNESS OF THE ELDERLY

The Committee on Mental Health and Illness of the Elderly was established by Congress (P.L. 94-63) on July 29, 1975 to conduct a study and make recommendations to the Secretary of Health, Education and Welfare for submission to Congress in three areas.

(1) The future needs for mental health facilities, manpower, research, and training to meet the mental health needs of elderly persons.

(2) The appropriate care of elderly persons who are in mental institutions or who have been discharged from such institutions.

(3) Proposals for implementing the recommendations of the 1971 White House Conference on Aging respecting the mental health of the elderly.

The Committee report was completed in the Fall of 1977 and submitted by the Secretary the following May to the two designated Congressional Committees: the Committee on Labor and Public Welfare of the Senate and the Committee on Interstate and Foreign Commerce of the House of Representatives. Psychiatrist Eric Pfeiffer served as Chairman of the 10-member committee, which by law consisted of representatives of the various mental health disciplines.

The findings and recommendations of the Committee are all relevant to the development of national policy for the frail elderly. Of particular interest, because they address the boundary issues between mental health status and illness and the necessary elements of a multidimensional-approach to long-term care, are the following:

Prevention

The Committee believed that if a national policy of systematic preventive services in the area of mental health of the elderly were initiated, many of the problems, concerns, and costs stemming from the current inadequate system of services to the mentally ill would be greatly ameliorated. To that end, the group recommended that:

- Effective systems for teaching the elderly to cope with the aging process be developed. Expanded support should be given to exploring and applying effective strategies for disseminating this knowledge through the media, educational institutions, senior citizen groups, and other community organizations.

- A major program of public education be developed to combat prejudice toward the old and to improve the image of the aging experience in the eyes of the general public, the media, service providers and the elderly themselves. Actions to combat age discrimination should be vigorously pursued.

- To help provide appropriate services and avoid unwarranted institutionalization, a nationwide system of Comprehensive Geriatric Assessment Units be created within existing community programs to serve as assessment, assignment, treatment, and coordinating centers on an areawide basis.

- Crisis intervention programs at the community level be developed and expanded to provide services for the elderly who are at high risk of developing mental illness.

- A comprehensive, long-term social support system be developed in each community for elderly persons who are chronically ill, socially isolated, and/or frail which can provide, on a sustained basis, those services needed to promote and maintain maximum levels of functioning. Existing agencies and organizations should be used to the fullest extent possible, while new models must be designed and tested to ensure that present gaps in services are closed.

- The most vulnerable groups of community dwelling elderly--the deinstitutionalized chronically mentally ill, and those with severely reduced physical and emotional capacities due to extreme old age -- should be entitled to special assistance in planning for and access to the services they need. Federal support should be given to developing and testing models for sustained community agency responsibility for regularly monitoring and assuring needed services for these high-risk elderly.

Services

According to the Report of the Committee on Mental Health and Illness of the Elderly, the aged require a broad range of health, mental health and social support services that is a changing mixture of assessment, treatment and rehabilitative services on a home-delivered, ambulatory, residential or institutional-care basis, depending on the specific functional state of the individual at a given point in time.

In order to improve the availability and accessibility of mental health care for elderly persons, the Committee recommended that:

- Coverage for mental health services be provided on an equal basis with coverage for physical health care services, for both acute and chronic illnesses. In existing third-party programs, current inequities in coverage for mental health care services must be redressed, making mental health care services as accessible as physical health care services, for both acute and chronic illnesses.
- A national policy to ensure the availability of a full range of mental health services for the elderly, from ambulatory to home-health, congregate living, day and/or night care, transitional care (half-way houses), foster homes, rehabilitative services, and specialized inpatient services be developed.
- A focal point be designated at the State level to ensure that the mental health needs of the elderly are being and will be met through careful assessment, coordination, and planning of statewide health, mental health and social services. Financial and technical assistance should be provided to States to strengthen their capacity for geriatric mental health service assessment, coordination, planning and development.

Research

The Committee indicated its belief that, if scientific knowledge were expanded, many of the mental health problems that now incapacitate and debilitate many elderly persons should not, and need not, be regarded as an inevitable part of growing older. "The presence of large numbers of mentally healthy and alert individuals who sustain their intellectual and emotional integrity well into advanced old age attests to the fact that mental illness in the aged is just that -- illness -- and not the necessary price of living long."

Training

A number of initiatives were identified, both to upgrade the geriatric mental health competence of current practitioners and researchers, as well as ensuring an appropriate growth rate of well-trained individuals in the future.

Minorities

The Committee found that minority elderly share many characteristics in common with other older Americans, but there are many features of their lifestyles, attitudes, cultural values, language, and socio-economic and educational status that require special consideration. Although there is evidence that the prevalence of mental illness may be greater among the minority elderly than in the majority group, they currently receive disproportionately little in the way of mental health service, and frequently confront service providers who do not understand their particular perspectives and needs. The Committee feels it is important that the service system be accommodated to the minority population rather than ask these aged persons to change the habits, attitudes and expectations of a lifetime to suit a service system geared to the mainstream culture.

Major Strategies for Implementation

These recommendations -- highlights summarized here -- set forth, in the Committee on Mental Health's estimation, the basic framework for development of a comprehensive national policy to meet the mental health needs of the elderly. Their implementation strategy depends both on the utilization of existing resources and the development of new ones.

Of particular importance for the furtherance of some of the goals of the Federal Council on the Aging are the following:

- Amend Medicare and Medicaid legislation to extend the same coverage and benefits for mental illness that are now available for physical illness.

- Amend Medicare and Medicaid legislation to place the providers of mental health services on an equal basis with the providers of general health services.

- Strengthen the quality assurance mechanisms built into Medicare and Medicaid to include the mental health components in staff requirements, provider qualifications, and professional review of services.

- Amend Title XX of the Social Security Act to require that social support services necessary to comprehensive mental health care be a component of the State social service plan.

- Amend Title III of the Older Americans Act to provide that the State and area agencies on aging are responsible for the inclusion of mental health services.

STUDY 9 - Commission on Civil Rights

THE AGE DISCRIMINATION STUDY

The Age Discrimination Act of 1975 directed the U.S. Commission on Civil Rights to conduct a study of unreasonable discrimination on the basis of age in the administration of programs and activities receiving Federal financial assistance.

After weighing the evidence assembled as a result of staff studies and public hearings, the Commission concluded that:

- Barriers have been erected by both public and private administrators between persons falling within particular age groups -- especially children and older persons -- and services which are financed in whole or in part by the Federal Government.

- Erection of these barriers has had and is having a serious adverse impact on the lives of children and older persons who need these services. It is a depersonalized approach in direct conflict with the concept of the dignity and worth of the individual.

The Commission determined that the reasons advanced for the erection of these barriers between members of particular age groups and federally-supported services did not constitute a valid basis for arbitrarily disregarding the needs of individuals within these age groups. They held that all such barriers constitute "unreasonable discrimination" on the basis of age and their establishment should be prohibited by law. Two programs studied by the Commission -- Community Mental Health Centers and Title XX-- have particular relevance to the frail elderly.

Community Mental Health Centers

The Civil Rights Commission found that "the area of mental health services represents one of the most glaring examples of discrimination on the basis of age." The following data were cited:

- In 1975, 328 community mental health centers with service area populations averaging 9.9% aged 65 years and over, had patient loads with only 4.1% older persons.
- In 1976, 528 CMHCs directed nearly 36% of their staff hours for consultation and education to agencies concerned primarily with children and only 5% of their staff hours to agencies dealing with older persons.
- Eighteen to 25% of those 65 or older have mental health problems that interfere severely with their ability to function on a daily basis. (Quoted from Gene Cohen, M.D., Director, Center for studies of the Mental Health of the Aging, National Institute of Mental Health.)
- Referral sources are found for the most part within the existing social service and educational networks. Older persons have little or no contact with the formal referral networks.
- Staff involved in health and social services lack pre-service or in-service training in gerontology and/or geriatrics.

One of the ensuing recommendations of the Civil Rights Commission would require federally-assisted programs such as Community Mental Health Centers to set performance goals for participation of persons in their programs based on the percentage of an age group in the total population eligible for the programs within the boundaries of the service area. This means that if a CMHC had an eligible service area population which was 9% elderly, then 9% of all its clients should be the aged.

Social Services to Individuals and Families

Title XX of the Social Security Act authorizes grants to States to pay part of the cost of providing social services to low income individuals and families. States must offer SSI recipient at least three services directed toward each of these goals:

- Financial self-support
- Personal self-care
- Protection of children and vulnerable adults from abuse, neglect, or exploitation; and strengthening family life
- Avoidance of inappropriate institutionalization by providing services in the local community, often in people's own homes
- Appropriate institutional placement and services when in a person's best interest.

The Civil Rights Commission staff had difficulty determining the amount of Title XX monies which are expended on the elderly because there are no requirements that such data be maintained by the States and forwarded to the Federal Government. However, the CRC believed there was sufficient basis to conclude that a substantial amount of Title XX money is used by the States for continued support of long-standing community social services for children, youth and their families. Because most States are at or near their allocation limit of Title XX monies, there is great reluctance to decrease or eliminate funding for an ongoing program for children in order to launch a new service for the elderly. Furthermore, the availability of social services for the elderly through the Older Americans

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Act was often cited as a rationale for denial of Title XX monies for programs for the aging.

The Civil Rights Commission (CRC) concluded that the arguments of limited resources in a program that is intended to serve all ages and the presence of categorical programs were not acceptable.

> Resources are always limited. Program administrators ... must set priorities. Priorities should not be established, however, by using age as a criterion for denying access to needed services. Other criteria based on an evaluation of the relative needs of individuals are always available. The fact that they may be more difficult to administer does not constitute a sufficient basis for rejecting them.
>
> Age categorical programs are authorized to meet additional or special needs of people of certain ages. If a program intended for all age group ignores the needs of the group being served by the special program, the age categorical program cannot achieve its purpose, and the general program fails to meet its responsibilities.

General Recommendations

Among the recommendations in the CRC report with relevance to this examination of the public policy context for the frail elderly are the following:

- State and local laws which are designed to implement federally-subsidized services and benefit programs should be placed under the purview of the Age Discrimination Act. (Example, when a State legislature directs expenditures of Title XX Social Services program funds to certain age groups before the requisite public input is obtained, or before the assessment of needs is presented, the resulting inequities frustrate achievement of the Federal statutory purpose.)
- Any person aggrieved by violations of the Age Discrimination Act should have the right to institute a civil suit in a court of competent jurisdiction.

- If a State or local government agency administering a federally-assisted program is determined to be out of conformity with the Act and that body is the only eligible entity for administration of the program, the relevant Federal officials can redirect that program's funding to any public or nonprofit private agency which can meet the Federal statutes.

- Operating units of the Federal departments should require their grantees or contractors to set performance goals and plans of action for the participation of persons in their programs, based on the relationship of the age groups within the eligible population to the total population eligible for the programs within the boundaries of the service area.

- Administrators of agencies receiving Federal financial assistance should inform all eligibles or under-served eligible age groups about the benefits available.

- HEW should review all of its training assistance programs to institutions or to individuals and ascertain whether its funding policies are resulting in making available sufficient personnel equipped to meet the needs of particular age groups.

ANALYSES OF SUMMARY REPORTS

While every effort has been made to have the preceding summaries of these government reports accurately reflect their contents, those sections which have relevance to the frail elderly and to the formulations of the Federal Council on the Aging have obviously been selected for FCA emphasis. It is hoped that the context of the ensuing commentary will also preserve the veracity and intent of the original data and views.

A major group dealt with in each of these reports is the frail elderly in many traumatic circumstances:

- That group who became deinstitutionalized from State mental hospitals only to become "warehoused" in Medicaid-financed nursing homes or boarding houses financed through SSI payments;

- The growing number of veterans with no family and community roots who will use the VA for their long-term care needs;

- Older persons needing legal or social protective services under the authority of State courts;
- Unserved but eligible beneficiaries of home-care programs financed by some title of the Social Security Act or the Older Americans Act;
- Impaired older persons who need a multidimensional assessment in order to take advantage of services and benefits which are already in existence;
- The frail elderly with aging family members who want to help but do not know how to cope with their own impairments let alone those of the previous generation.

These reports are not an exhaustive compendium of every current public issue which should be addressed regarding the long-term-caring needs of the frail elderly but many of the questions which were raised in the beginning of this FCA report are touched upon. It is hoped that these summaries illustrate the perspectives which each brings to an analysis of one dimension often completely apart from overwhelming data of a related dimension. Hopefully, this can be illustrated by cutting across a few topics.

Family and Friends

The General Accounting Office studies in Cleveland and on home health care shatter at least two myths: that families do not care for their elderly, and that home care always costs less than institutional care.

The GAO is very clear that two-thirds of the seriously impaired older persons in the United States are being cared for at home primarily by family and friends with some assistance from unevenly available formal community services. This care "costs" less in public money than if the same degree of care were being provided in a nursing home under Medicare or Medicaid reimbursement but the social "costs" as well as the actual financial costs for the family can be sizable.

The GAO cautions that expansion of home care for those persons without family and friends must be examined in terms of equity and practicality. It may well be that those family members and friends now providing all this care for their frail elderly kin and friends may feel that they have a right to be relieved of some of the duties which they have assumed of their own free will if such care becomes available through a government entitlement.

Long-Term Care of Veterans as a Model

In developing national policy for the frail elderly, the Veterans' Administration program for long-term care of its constituents bears examination for more reasons than the fact that veterans will soon constitute the majority of the American male population over the age of 65.

There is much to be learned from the flexible approaches of the VA's non-institutional extended care programs. VA personal care homes were originally devised as a means of discharging psychiatric patients into the community by providing a basic level of social support in a family setting. This is now the largest VA Extended Care Program with over 22,000 veterans in placement. Patients with significant residual disability may be helped to remain in their own homes through the Hospital Based Home Care (HBHC) program. The patient and his family are provided the necessary instruction in the routine and nursing procedures under the coordinated supervision of the hospital-based treatment team.

A large majority of the patients in VA long-term care facilities have no real home of their own. Ninety percent of domiciliary residents are unmarried, and most of them have long been estranged from any families that may have existed. In many ways, the Veterans Administration has become their surrogate family.

Constant-Attendance Allowance

What is not covered in either the National Acadamy of Science report, the VA report on its plan for the aging veteran population, nor any of the other reports summarized here, is the VA "aid and attendants" program.

This cash benefit is administered by the VA Division of Veterans Benefits and provides a flat payment to non-service connected needy veterans and a flexible amount of money to service-connected veterans who are determined to be either permanently and totally disabled or homebound through some incapacitating physical and/or mental condition. The determination of eligibility is made by the Division's Adjudication Board based on the veteran's medical charts and other pertinent official reports.

The theory behind the cash supplement is that the modest amount of money (around $160 a month) to the non-service connected will be used not to purchase the services of a skilled person but will provide sufficient extra income to a family to ease the burden of having an incapacitated person in the home. Family members are trained where necessary by VA personnel in care of the veteran.

The VA Adjudication Department, much like the Social Security Administration, does not have social workers or medical personnel on its immediate staff and it does not believe constant monitoring is necessary. Of course, there is easy access to the wide range of clinical personnel in the Department of Medicine and Surgery. Social workers in that unit consider themselves "case-finders" for potential aid and attendant recipients. In turn, the benefits staff will refer cases to Medicine and Surgery when a problem arises requiring clinical skills. The apparently few cases of misrepresentation of disability are referred to the investigative arm of the Adjudication Department. (VA studies have shown little misuse of the money received.)

Social workers do maintain ongoing relationship -- case-management -- with all veterans in the aid-and-attendant program with a psychiatric diagnosis, those not living in their own homes, and those undergoing involved medical technologies in the community, like kidney dialysis. In other words, it is assumed that many veterans with physical impairments requiring only simple nursing care can manage at home with a little extra cash each month.

Despite what appears to be fairly successful experiences with constant-attendance allowances with American veterans and in 47 foreign countries, there has not been much interest in this mode of assistance as part of a long-term care strategy in this country (Tracy, 1974).

A staff paper circulating in the Social Security Administration in 1971 suggested consideration of an additional cash benefit for social security beneficiaries aged 75 and over who, because of physical impairments, are in need of long-term nursing home care or special assistance at home (such as homemaker services) on a continuing basis. The flat amount would be greater for those who needed nursing home care and less for those who needed special assistance or attendance at home. Beneficiaries would not be required to meet a means test in order to qualify for the additional cash benefit but would qualify on the finding of a need based on a combination of medical and social factors.

Another approach suggested in this SSA staff paper was a small supplementary cash benefit payable as a matter of right to all beneficiaries aged 75 and over, with the benefit graduated to increase with age. The small amounts proposed would pay for occasional personal or household services (like meals-on-wheels) or for someone to market and run errands, and so might enable some aged people to remain in their homes. This proposal, described as one which would save the administrative costs involved when a finding of need based on a combination of medical and social factors is required, utilizes the same rationale as the Federal Council in using advance age as a proxy for need.

A major advocate for a "personal care benefit" is Robert Morris of Brandeis University. He has called for this personal care benefit to be payable to the consumer by cash or voucher, determined by functional conditions and not by income deficit alone. Morris advocates the consequent emergence of a network of personal care organizations growing out of existing fragmentary service agencies independent of, but linked to, and parallel to, the existing structure of medical services.

Judith Treas, writing in The Gerontologist in December 1977, asks for consideration of direct subsidies to families who participate in the day-to-day care of aging relatives. "Families who overcome the many obstacles to home care for the aged would seem to warrant direct payments as surely as do strangers providing less personalized services", she says.

The Nature of Mental Illness in the Older Population

The studies on deinstitutionalization, protective services, financing of long-term care, age discrimination and mental health seem to be based on different assumptions of the nature of mental illness among the elderly. The Congressional Budget Office proposals for long-term care financing exclude the mentally ill and retarded and deal only with those who are physically disabled. The GAO deinstitutionalization study, dealing primarily with an aged population moving out of State mental health facilities, gives brief recognition to the physical debilities likely to be present in many of these same persons.

The Age Discrimination Study implies that the elderly with mental frailties all require the treatment modalities of the community mental health centers in the same degree as other age cohorts in the population and, therefore, should have their quota according to their number, not according to their needs, and irrespective of mental-health programs geared to the unique frailties of advanced age.

The Protective Service Report and that on Mental Health and Illness of the Elderly are both based on the premise that the debilities of the elderly are so interrelated that physical and mental health and social needs must all be considered in diagnosis and assessment procedures and carrying out a plan of long-term care. Furthermore, the likelihood of several chronic physical conditions, loss of spouse and/or close kin, and diminishing financial assets makes the older mental patient a likely candidate for treatment and care which is substantially different from that required by non-aged adults.

The recommendations of the Senate Committee on Aging's Protective Services Report for a "Geriatric Evaluation Service" (GES) and that of the Secretary's Committee on Mental Health and Illness of the Elderly for "a nationwide system of Comprehensive Geriatric Assessment Units" (CGAU) are quite similar in concept to the proposals of the FCA. The GES units would be lodged in the State agency to which responsibility for legal and social protective services would be assigned by law. The CGAUs would be located within existing community programs, the exact administrative location depending upon local community circumstances and resources.

The Mental Health and Illness of the Elderly Report does not directly address the relationship of the courts and formal protective services in the community to their CGAUs. It would be hoped that, as this report and that of the recently-issued President's Commission on Mental Health are implemented, the parens patriae role of government for mentally-frail persons exercised through the courts and protective services will be integrated into concerns for improving and expanding mental health treatment and care at the community level.

While the Age Discrimination Study was limited by law to an examination of federally-assisted programs, some of the conclusions and recommendations are flawed and circumscribed by not taking into account activities beyond this narrow scope. There is no denying that many older persons have mental problems which interfere with their ability to function on a daily basis. However, one cannot then make the conclusions implicit in the Commission's findings and recommendations, namely, that these mental problems are the major problem of this population and should be dealt with through the short-term psychotherapeutic modalities which are the major one-to-one treatment modality of the CMHC.

Because State mental hospitals are supported primarily with State monies, the care they provide to the elderly-disturbed cannot be ignored in a computation of society's concern. Despite the growing attempts to discharge the elderly who do not belong in mental hospitals and to avoid their initial placement, it is likely that the elderly are still the predominant age group in such facilities and get more than their "fair share" of institutionalization.

For those elderly with mental impairments who can remain in the community, the Federal Council contends that, because many are also likely to have physical health and social problems of equal intensity, they can benefit from a regime which is primarily "social" and "psychosocial" with "health" components rather than primarily "psychotherapeutic." In this context, one cannot ignore the federally-aided psychosocial and long-term supportive services which are already available, albeit not too systematically or equitably, through the Older Americans Act and Title XX of the Social Security Act.

To return to the matter of whether there is genuine discrimination against the aged in programs mandated to serve all ages and whether the elderly get their "fair share" is to raise questions of distributive justice which must involve the totality of what the elderly share of Society's goods. Social ethicist Albert Jonsen (1975) tried to grapple with this and said that no claimant group has a natural priority to social goods resulting from the existence of a productive work force.

National Long-Term Care Policy

"For every complex problem in society there is a solution that is simple, plausible and wrong." So spoke the sage of Baltimore, H.L. Mencken, and not any of the writers of the government reports which have been summarized here. While many of the reports do acknowledge the complexities of determining the role of government in the care of its vulnerable citizens, the prescribed limits of the reports do produce a limited perspective on the complex problem of long-term care.

Many proposals accept what is in place as a given fact without evaluating basic concepts and programs. The Federal Council's recommendations have tried to deal with some organizing principles and a concept of a floor of basic social services. Faced with sizable needs of a growing older population, some concept of priorities is required.

NON-GOVERNMENT STUDIES AND RECOMMENDATIONS

To complete this picture of the current setting in which public policies for the frail elderly must be developed, this section reviews several recent sets of policy recommendations coming from the private sector regarding long-term care.

REPORT NO. 1 - TASK FORCE ON LONG-TERM CARE

NATIONAL CONFERENCE ON SOCIAL WELFARE

The work of this Task Force of the National Conference on Social Welfare was supported in part by the Division of Long-Term Care of the Health Resources Administration of HEW. Its final report, "The Future of Long-Term Care in the United States" was issued in February 1977.

In the preface to the report, Bernice Catherine Harper, then Director of the Division of Long-Term Care, expressed the following objective for such activities as the NCSW project:

> The ultimate goal is quality care for all persons, of all ages, all races, and all socio-economic levels. This required special emphasis on the social/health care plan -- a continuum of care -- to meet the health (including rehabilitative) and psychosocial needs of the physically and mentally disabled.

The Task Force identified a number of knotty issues, which it labeled "dilemmas" because of their complexity, their defiance of simple solutions, and their propensity to produce either intense advocacy or opposition:

Dilemma 1: Where should administrative authority for long-term care be located?

Dilemma 2: How to change the attitudes of professionals and staffs?

Dilemma 3: How to bring change in community value systems?

Dilemma 4: How to develop the funding patterns and resources conducive to the development of a continuum of long-term care services?

Dilemma 5: How to balance society's concern for the rights of the vulnerable individual and society's responsibility for the safety of the community?

Dilemma 6: How to retain and strengthen family support and other informal support systems?

Dilemma 7: How to establish an intermediary system to perform specific tasks to expedite services more equitably and provide a continuum of care?

Dilemma 8: How to determine if there is a cutoff point in chronological age or otherwise when it becomes futile from cost and benefit to provide any more than minimal services?

The report concludes with a range of options upon which solutions to some or all of these dilemmas might be based. However, the Task Force is clear that it favors a strong social component in national policy initiatives for long-term care.

This National Conference on Social Welfare Task Force on Long-Term Care has evolved into a Washington-based "forum" sponsored by several of the major national voluntary organizations concerned with long-term care for persons of all ages and various debilities. Ruth Knee, who chaired the original Task Force, now chairs the new group as a representative of the National Association of Social Workers which is the convenor of the forum.

REPORT NO. 2 - UNIVERSITY OF CALIFORNIA HEALTH POLICY PROGRAM

Tom Joe and Judith Melzer of the Health Policy Program School of Medicine, University of California at San Francisco, issued a report on "Policies and Strategies for Long-Term Care" in May 1976. The paper addresses public policy issues in the area of long-term care in a way that focuses attention on the cross-cutting, non-categorical nature of the problem and the various levels of government that must be involved in determining solutions. The authors propose six areas for action by Federal, State and local governments. Highlights follow:

Detailed Data Collection and Problem Analysis

There needs to be a conscious strategy to collect and analyze information on the numbers of long-term care facilities, the characteristics of the facilities, the characteristics and service needs of the clients, the services provided by the facilities, the true costs of providing long-term care services, the sources of funds for long-term care, and the availability and use of community alternatives. Ideally, this should be done on a national basis. However, this likelihood in the near term is dim and States are urged to take the initiative to gather information they need now in order to solve current problems. States must also assess administrative and political barriers, bureaucratic and professional turf interests and gaining necessary high level policy consensus on the definition of the problem of strategies of change.

Technical and Administrative Reforms

In the absence of any broad reforms in the area of long-term care, pressure will mount at the Federal, State and local levels to make incremental legislative changes. An example of this approach is the series of 48 bills relating to nursing home care introduced in 1976 by (then) Senator Moss, (then) Congressman Koch and Congressman Pepper related primarily to administrative reforms, licensing and standard-setting, and accountability in current programs. Individual pieces of legislation like this do have merit, but they cannot be pursued in the absence of a long-range objective or as a replacement for more sweeping change. They must be viewed in relation to the totality to insure that they do not complicate an already complex area and further the inequities and conflicts among levels of government, jurisdiction, client groups and programs.

Long-Term Care Financing

Establishment of a federally-financed program to cover costs of room and board in long-term care facilities. Rates would be established with regional and/or community variations to reflect cost-of-living and costs of housing with potential for a sliding-fee scale.

Amendments to existing social service programs (i.e., VR, Title XX, Mental Health) to make flexible provision for meeting long-term care service needs of people in institutions, as well as of those who remain in their own homes. Continued funding for medical services provided in long-term care facilities through Medicaid and Medicare, or any new health financing program.

Delivery Systems: Community Assessment, Placement, Referral and Feedback Mechanisms

One approach to the development of community delivery systems is the Conable, Pepper, Koch and Fraser bills, all of which establish community long-term care or home health centers with similar responsibilities for assessing client needs, coordinating care on behalf of individual clients and providing a feedback system on the kinds of and quality of services available. Even in the absence of specific Federal legislation, however, States and localities could move in this direction, utilizing Older Americans Act funds, Title XX funds and community Mental Health funds for operating support for a coordinating agency which has knowledge of multiple agency funding sources, various eligibility requirements, and community service alternatives.

Manpower, Training and Development

In order to implement any of the recommendations, a conscious manpower training strategy must be instituted to train and retrain workers who provide long-term care services at the local level. Assisting individual clients to make appropriate decisions regarding service needs and institutional or in-home care, workers must be extremely knowledgeable about the availability of community resources, a client's needs and entitlements and how to orchestrate a service package to meet individual need.

Research and Technological Development

In addition to the more immediate strategies for reforms of financing, administration and delivery of LTC services, there is a continuing need for research in several areas, including:

-- characteristics of institutional long-term care
-- development of placement measures
-- development of quality of care measures
-- refinement and use of technology

REPORT NO. 3 - NATIONAL ACADEMY OF SCIENCES

INSTITUTE OF MEDICINE - ANGLO-AMERICAN CONFERENCE

The Institute of Medicine of the National Academy of Sciences conducted an Anglo-American conference on care of the elderly in Washington, D. C., on May 17-19, 1975*. To assess the findings of the conference and to make recommendations for U.S. policy affecting the functionally-dependent elderly, the Institute formed a Committee on Care of the Elderly under the leadership of T. Franklin Williams, M.D., Medical Director of Monroe Community Hospital and Professor at the University of Rochester. Garson Meyer, Vice-Chairman of the Federal Council on the Aging, was a member of the Committee. A resultant policy statement, entitled "The Elderly and Functional Dependency", was issued by the Institute of Medicine in June 1977.

In the view of the Committee, the elderly should not be forced to deplete their assets in order to obtain access to long-term care because elderly persons are in no position to replace assets. To effect a fundamental change in Federal policy for care of the elderly, it was recommended that:

> The Federal Government should reimburse for long-term care provided to the functionally-dependent elderly. Long-term care should include both health and social services and should provide for choices between institutional and home-based care. Eligibility for Federal reimbursement of long-term care should be based on a comprehensive assessment process.

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*Both the Administration on Aging and the National Institute on Aging participated in funding the conference.

The Committee stated its belief that other demands on State financial resources are severe and the needs of the elderly too universal to recommend State financing for such a program. Therefore, it was proposed that the long-term care program be financed either as part of a national health insurance plan, an extension of the Medicare program, a new program supported through general revenues, or by a combination of general revenues and voluntary premiums. States and localities would retain key roles in administering provisions of the program.

In view of the uncertainties associated with the costs of a federally-supported long-term care program for all persons 65 and over, the Committee suggested that initially the program should be restricted to persons 75 and over.

The NAS Institute of Medicine Committee also recommended that:

> A single agency should be identified to coordinate the delivery of health and social services to the dependent elderly at the community level.

The primary goal of this agency would be to promote coordination of services for the elderly rather than to develop age segregated health and social services. However, the Committee believes that a separate approach for coordinating services for the elderly is a necessary first step in assuring recognition of the needs and problems of this segment of the population.

REPORT NO. 4 - AMERICAN PUBLIC WELFARE ASSOCIATION

SPECIAL ISSUE APWA JOURNAL - SPRING 1977

In a special issue of the APWA Journal Public Welfare for the Spring of 1977, policy statements on "Social Services for the Aging" and "National Health Policy" appeared. Among the proposals with relevance to the frail elderly and long-term care were the following:

Social Services for the Aging

As major steps towards the implementation of a universal system of public social services, the American Public Welfare Association recommended: (1) clarification of the scope of social services for older persons that should be developed under Title XX of the Social Security Act; (2) broadening of the universal social services for older people included under Title XX; and (3) an improved Federal financing base for the Title XX program. Also proposed was continued expansion of the Older Americans Act and support of the Social Security Administration's efforts to give more attention to the social services needed by beneficiaries of old age, survivors, and disability insurance (OASDI) and supplementary security income (SSI). Specifically recommended were the following objectives:

1. Gradual raising of the ceiling on Federal matching expenditures for social services to permit the progressive development of a universal public social services system serving older people, as well as other adults, families, children and youth.

2. A Federal program of "personal" social services for older persons to enhance or maintain their social functioning must be clearly defined and developed if a basic floor of universal services for older people is to be established in the future.

3. Universal eligibility and entitlement for public social services for older people regardless of their economic status.

4. Improved standards and accountability in public social services for older people to improve the effectiveness, efficiency, intended scope and quality of these services.

5. Continued expansion of various programs of the Older Americans Act related to the planning, development, and provision of social services to older people.

6. Improved coordination of social services for older people. The Federal Government should work with State and local governments and with the voluntary sectors.

7. Encourage efforts by the Social Security Administration to develop and demonstrate information and referral services and other linking services within its general operations for OASDI and SSI beneficiaries.

National Health Policy - Long-Term Care

Within an overall policy statement on national health policy, APWA's Committee on Health Policy made several recommendations dealing with long-term care:

1. National health insurance should be responsible for financing all of the medical-health services required by persons in need of long-term care. In addition to the services of physicians, other health care practitioners, hospital care and out-patient care, these should include such long-term care-related services as:
   - home-health aide services;
   - nursing and medical services provided in the individual's residence, including medical devices and supplies for use in the home;
   - therapeutic and rehabilitative health and mental health services required to maintain an optimal level of functioning;
   - health-related day care services, beyond those needed for socialization;
   - transportation to and from medical care facilities;
   - institutional care, exclusive of hotel costs, for persons with disabilities or social conditions that would not allow maintenance at home.
2. Persons covered under NHI who need a combination of non-medical support services should automatically be eligible for those services, although an appropriate copayment might be required in some cases.
3. NHI should finance appropriate assessment, review, and placement services for persons requiring long-term care.

CORE SERVICES IN DETAIL

ALTHOUGH THE FEDERAL COUNCIL on the Aging is proposing that the core services -- assessment of need, development of a plan of care, and case management -- be available to the frail elderly as an integrated package, it is separating the three in this detailed section of the report. Assessment and care planning will be considered together, and case management separately in recognition that this latter service can logically and meaningfully be provided by a separate agency, different practitioners, and through a different financial arrangement.

TWO PARTS OF THE THREE-
ASSESSMENT AND PLAN OF CARE

The distinctions are not neat and there are excellent illustrations of many different approaches to packaging assessment with other services. The programs which will be described in this section have been selected because they illustrate points about the proposals the Federal Council is advocating.

They describe two major approaches to assessment: one, which might be called an "independent" assessment process not linked to any eligibility determination process; the other, providing the same type of assessment but linked with the determination of eligibility for some separate benefit or service.

Lawton (1971) provides a succinct definition of "functional assessment" as any systematic attempt to measure objectively the level at which a person is functioning in any of a variety of areas, such as physical health, quality of self-maintenance, quality of role activity, intellectual status, social activity, attitude toward the world and self, and emotional status.

Independent Assessment

The in-depth assessment of a frail older person's problems, resources and functioning, and the development of a plan of care in conjunction with the older person and the significant people in her or his life, have as their primary goal greater knowledge and awareness of the person's own resources and needs -- be they government benefits to which one is entitled, financial and physical assets, physical and mental health, or the degree of ability to cope with daily living. Counseling with the older person and significant family members and friends around the emotional implications of their relationships and responsibilities under the stress of the growing impairments of the older person would also be a basic component of the assessment process.

Geriatric Family Service

One illustration of a response to this need by the private sector was brought to the attention of FCA by Charlotte Kirschner, a social worker who established the Geriatric Family Service in New York in 1975. On a fee-for-service basis, this private agency provides, according to its brochure, "evaluation, guidance, help to meet your own individual family's needs when you are worried about your elderly mother, your aging father, your grandparents...." The Geriatric Family Service is not designed at the present time to provide counseling.

Ms. Kirschner established the GFS following her retirement as director of social services at the Jewish Home for the Aging because of the many request she received from physicians and psychiatrists to see their private patients for assessment.

Assessment Programs by Community Agencies

The type of psychosocial assessment which is offered by the Geriatric Family Service on a fee-for-service basis is also provided in many communities by such non-profit private groups as family service agencies and community mental health centers with no fee or a sliding fee scale. Continued counseling for at least a short period of time to assist in implementing a plan is frequently available from these agancies.

Family service agencies have a track record of serving the elderly about equal to that cited previously for community mental health centers. A recent study (Rothman and Kay, 1977) indicated that persons 65 years of age and over represent 4 percent of all clients served in family agencies. However, many such agencies have long had assessment procedures available in terms of determining eligibility for homemaker programs which many of them sponsor.

A number of multi-purpose senior centers provide a full-range assessment program for the impaired elderly as a complement to activities for the entire older population. In some instances, this activity consists of providing space for a family service agency representative in the senior center. In other cases, a social caseworker is on the center's staff.

Long-term care providers, such as visiting nurse associations and nursing homes, also provide assessment with the understanding that it could result in recommendations for use of informal resources in the community or for formal services from other providers. Obviously, there is a potential conflict of interest when assessment is provided by a potential provider of services which could be reimbursed by a government financing mechanism.

The evolving role of Professional Standards Review Organizations (PSROs) in evaluating the need for long-term care places them in an assessment role for the frail elderly as well. Under the Medicare - Medicaid Unit-Fraud and Abuse amendments to the Social Security Act enacted in October 1977, certain PSROs are to assume responsibility for reviewing admissions to certain skilled nursing homes, intermediate care facilities and ambulatory care services. Where a PSRO assumes a long-term care responsibility, it is encouraged to establish a technical advisory body made up of providers of long-term care which will assist in the collection and analysis of data and develop criteria for determining the level and quality of care which should be provided by long-term care facilities within the jurisdiction of the PSRO.

Assessment Linked with Eligibility Determination

A number of the professionals who have consulted with the FCA on this frail elderly project have suggested the possibility of using the assessment process simultaneously as the determination for eligibility of certain means-tested Federal or federally-aided benefits such as SSI, Medicaid, food stamps, housing or the social and health services which would be useful in supporting an older person outside an institution. The assessment might also be utilized as the foundation for the more extensive and intensive health evaluation necessary to determine the appropriate level of institutionalization when that type of care is required and available.

This idea ties in with the recommendation which the FCA advanced in its project on the interrelationships of benefit programs, namely, that consideration be given to the feasibility of a simplified system at the local level for determining eligibility and benefit levels for all federally-funded income-conditioned programs.

Whatever is done in this regard must deal with certain statutory and legal responsibilities for determining eligibility for government programs which cannot be arbitrarily re-delegated to other units of government nor to non-government bodies. In addition, when services involve the determination of mental incompetence, the parens patriae responsibilities of the court and of designated government agencies must be considered.

An interesting approach is evolving in Maryland regarding general assessment and recommendations for eligibility for certain services administered by State and local government bodies.

Geriatric Evaluation Service, State of Maryland

In July 1977, legislation became effective in the State of Maryland mandating the establishment of Geriatric Evaluation Services in each county with specific responsibility for all aged persons being considered for admission to a State mental hospital. A program which had been operating already in several jurisdictions of the State now became a required activity and State monies were provided to counties to aid in carrying out the law.

The main components of the GES are set forth in the model legislation on "Adult Protective Services" described on page 90 of this FCA report. Professor John Regan of the University of Maryland School of Law, who co-authored the Senate Committee on Aging report on protective services, was instrumental in passage of the Maryland law.

The GES grew out of nationally-lauded efforts in Maryland in the sixties to move older patients of State mental hospitals back into the community through foster homes and other such community-based programs and then to avoid institutionalization in the first instance through pre-admission evaluation. In Fiscal Year 1977, about 4,000 referrals were made statewide. Approximately 5% were admitted to mental hospitals, a slightly larger percentage to nursing homes and another small percentage to general and special hospitals. The cost per evaluation and assistance in locating appropriate resources averaged about $200. A minimum of $40,000 is required to set up each local service. (Padulla, 1977)

Montgomery County in Maryland carries out its GES through its "Assessment Center for Adults". This program was initiated in 1973 and because of substantial input of County funds has greater range than the State-required service.

A bi-agency, multi-disciplinary team of physicians and nurses from the County Health Department's Adult and Geriatric Services and the Community Care Services unit of the Department of Social Services provide professional assessment and planning without charge to any adult resident 18 years of age and over who is believed to be in need of care because of physical and/or emotional disability.

A home visit is made in the course of gathering information and additional consultation such as with a psychiatrist is obtained as necessary and can be financed from State GES monies. The plan is then discussed with the private physician, the client, and appropriate family members. If the plan is accepted, the team will assist the client and family in implementing the plan. When continuing consultation and supervision are required, the case does not remain in the assessment program. Referral is made to available resources, including social casework services by the Department of Social Services for which many adults living in the County would be eligible.

Techniques for Assessment

Assessing the functional capacities of the elderly and disabled for survey and clinical purposes is not a new skill for the various helping professions. The multidisciplinary team approaches which have been described represent pooling of clinical competencies and judgements which are not unique. They are well established in physical and mental health, correctional, rehabilitation, family and child welfare, and other fields dealing primarily with the non-aged.

But the field of aging is faced both with lack of knowledge on how to recognize and deal with the manifestations and problems of aging and with inadequate numbers of professionals with at least some gerontological skills.

Professional Roles and Skills

These conditions notwithstanding, there appears to be some consensus on required professional roles and skills in assessment of persons with several chronic impairments and the development of a plan for their care.

The Maryland and OARS-Durham models utilized social workers, physicians, nurses and psychiatrists in a team approach with consultation from other specialists as required. Some believe such an array might prove too expensive if it were introduced nationally and made available to the growing number of the very aged and disabled who could benefit from such a program. They suggest that a skilled interviewer working with one of the questionnaires which will be described later, pp. 122 - 126 could provide the one-to-one contact and be backed up by a team of professionals who would weigh the data and make a collective judgment.

A middle course would be to have either a social worker or nurse clinician make the direct contact with the person involved, with or without the questionnaire. This clinician should have available such peer professional back-up as would be required.

Medical Component of Assessment

Because it is believed that this assessment process can be operated without use of the medical model, that is, without utilizing the whole array of medical technoligies which must be brought to bear no matter how modest the health need, does not mean that the assessment process should ignore the frail person's medical condition. First of all, it would be expected that whenever a person did have a personal physician, appropriate existing medical data would be made available for the assessment.

A number of screening techniques have been evolved so that certain kinds of personnel, ranging from nurse-practitioners, physician's assistants and public health nurses to specially trained social workers, can be of assistance in facilitating the health-related diagnostic procedures or in identifying persons with evident medical problems.

But it should be noted that diagnosis is among the most sophisticated and skillful aspects of medicine, and while a number of para-professionals can identify gross symptoms, the ability to make clinical judgments normally belongs to a physician.

It would be conceivable, for example, that the person performing the psycho/social/environmental assessment could have the skills associated with public health nursing, including the ability to recognize gross symptoms, as well as the ability to administer some sort of a self-evaluation form and the beginnings of a medical history.

In addition to the issue of the actual kind of medical or health intervention necessary on the occasion of a preliminary psycho/social/environmental assessment, is the question of the structure which would be required by the introduction of significant medical in-put. Could even a "hands on" physical be administered generally within the context of the social program, or is it necessary that it or some lesser medical intervention require the general structural arrangement of the psycho/social/environmental to be medical? Obviously, if the latter were to prevail, the whole frail elderly system would be skewed in a direction different from that intended.

As a minimum, the assessment should include an overview of the frail person's health condition with an appreciation of his or her medical contacts, with additional medical services called for as needed.

Assessment Tools

To assist, systematize and possibly replace some personal clinical observations about the degree of impairment and functioning of potential recipients of long-term care, various "instruments" -- questionnaire, scale, or index -- have been devised.

A study undertaken for HEWs Office of the Assistant Secretary for Planning and Evaluation (Applied Management Sciences, 1976) identified the 17 following instruments as the genesis for the other patient instruments and questionnaires currently being used in this country.

Scales and Indexes

- Barthel Scale
- Debility Index for Long-Term Care Patients
- Index of Independence in Activities of Daily Living
- Instrumental Activities of Daily Living
- Kenny Self-Care Evaluation
- Mental Status Questionnaire
- Philadelphia Geriatric Center Morale Scale
- Rapid Disability Rating Scale
- Rosow Functional Health Scale
- Stockton Geriatric Rating Scale

Questionnaires

- The Long-Term Care Patient Survey
- The Monroe County Evaluation-Placement Unit Patient Evaluation
- The HRA Patient Classification for Long-Term Care
- The Project TRIAGE Evaluation Protocol
- The Needs Assessment Inventory
- The Personal Care Program Client Assessment Guide
- The OARS Multidimensional Functional Assessment Questionnaire

HEWs Public Health Service also commissioned a summary and critique of selected measures for activities of daily living which covers many of the same instruments.

Both of these studies and the instruments which they considered were reviewed for applicability to the FCA approach to assessment for the frail elderly. Most of them were designed to measure physical functioning in relation to the level of care that would be required in a chronic health care or rehabilitation residential facility. The two selected below come closest to providing the multidimensional focus which the Federal Council is advocating.

Physical Self-Maintenance Scale and Instrumental Activities of Daily Living

As described by Katz (1977), these measurements were developed by M. Powell Lawton and Elaine Brody of the Philadelphia Geriatric Center.

The Physical Self-Maintenance Scale (PSMS) is based on the Langley-Porter Physical Self-Maintenance Scale, modified by the authors for easier institutional use, to measure the degree of physical dependency. The six measures of physical self-maintenance are:

- Toilet
- Feeding
- Dressing
- Grooming
- Physical ambulation
- Bathing

The Instrumental Activities of Daily Living Scale (IADL) is an observational rating scale designed to assess everyday functional competence. It consists of the following eight areas of competency in the performance of daily activities:

- Ability to use the telephone
- Shopping
- Food preparation
- Housekeeping
- Laundry
- Mode of transportation
- Responsibility for own medication
- Ability to handle finances

The PSMS and IADL have been used in the evaluation of individuals residing in, or applying for, admission to institutions of varying types, with patients admitted to psychiatric screening wards, and with residents of institutions for whom a return to community living was under consideration. The scales have been utilized as an aid in the formulation, implementation, and evaluation of treatment plans. At the Philadelphia Geriatric Center, the IADL is used as part of a basic screening battery and to provide information relative to the appropriateness of five "levels" of available care.

The PSMS and IADL may be completed by any person who has knowledge of the patient's characteristics and level of performance. It is estimated that both scales can be completed within 10 minutes.

The OARS Methodology

Another instrument, known as the Multidimensional Functional Assessment (OMFAQ), developed by the Older Americans Resources and Services (OARS) program of the Duke Center for the Study of Aging and Human Development has been described earlier in this report (pp. 28, 76, 77). It was the survey instrument used by the Government Accounting Office in its research project to determine the impact of government programs on the elderly in Cleveland.

It has also been used for the following purposes:

- An admission or screening device to determine appropriateness of placement within an institutional setting.
- To study the impact of intervention of various service programs; that is, to determine changes in patient state as the result of a period of service delivered to an individual patient or client.
- For clinical purposes with individual patients or clients seeking services in a variety of health, mental health, and social services contexts.

The OMFAQ is included in this section with the three above purposes in mind. It is a detailed questionnaire concerning a person's functional level in five areas: social resources; economic resources; mental health; physical health; and activities of daily living. It also includes many questions relating to past and current use of various health and social services and to perceived need for such services.

Originally developed to evaluate the personal level of functioning and need for services for older persons residing in the community with a variety of impairments of differing severity, it has since been adapted for individuals 18 years of age and over who exhibit a chronic disability and for persons residing in long-term care institutions.

A health or social work professional or a trained interviewer takes a little more than an hour to complete this questionnaire. Each referred individual is subsequently seen by a clinician, usually a social worker or psychiatrist, who obtains additional clinical information. Upon completion of the evaluation process, the clinician is then required to make specific judgements for the person referred the three following areas:

1. Level of functioning in each of the five areas previously described.
2. Specific services needed.
3. Optimal setting in which these services could be provided.

Observations on Assessment

Assessment and development of the initial plan of care have been presented separately from case management because it is feasible to have separate administration and financing of these services. However, it has been very difficult to find ongoing or demonstration programs which did not identify the need for some assistance for at least a short period of time in implementing a plan of action either from the assessing agency or from another formal resource in the community. This was especially true in the absence of any significant other person capable of coping with the formal helping-system on behalf of the frail relative or friend.

Process of Assessment

The assessment would be carried out, in conjunction with the frail older person, insofar as possible, on his or her health, social, economic and evironmental conditions, problems and resources. This would include the person's role and relationship with significant other persons in his or her life or the absence thereof. The actual helping process would probably already have begun, during the assessment interviewing because many older people can benefit from the objective, supportive perspective of a trained practitioner helping to sort out the accumulative problems of age and an objective review of the informal helping network of family and friends.

The process would move on to an identification of benefits available from Federal and other governmental programs and such private provisions as pensions. The "assessor" and the older person, and possibly a significant relative or friend, would then develop a plan of action with emphasis on utilizing the resources of the natural helping system and family first, and then available community based services from formal systems. An important aspect of the plan would be a determination of a living arrangement providing the most independence for the older person related to his or her own desires and capabilities, the resources of Society, and the needs of the total population.

The development of a coordinated services plan would be another indication of this assessment proposal operating under a "social" rather than a "medical" model. The absolutes of an observable physical impairment with a narrow range of treatment options prescribed by a medical practitioner are not as applicable to a person having several non-acute impairments. Several options might be possible and the person to be helped, dependent on her or his degree of mental competence, has the right to choose that option which is least favorable according to conventional clinical judgment if he or she so wishes, (The medical model does offer options but contesting them is an overwhelming burden for the average mortal.)

In working with the older person and family and friends towards a plan of care, the following guides could be used:

1. What specifically can the older person at home continue to do on a regular basis to sustain one's long term care needs?

2. What help can family members and others in the natural system continue to provide, or add to what is currently provided, on a regular schedule to assist the frail person to continue in semi-independence at home?

3. What specific functional aid from community-based service programs and national legislation can be brought in to help with needs not covered by others? What entitlements from insurance or other such benefits accruing to the older person, can be used? Who is to take responsibility for following through on each of the additional possibilities uncovered?

Manpower

The assessment process would have to be coordinated by a skilled professional regardless of who did the initial interview. A social worker would probably be best equipped to serve as the coordinator because of the unique skills of the profession is psychosocial diagnosis and treatment and in knowing how to manage the acquiring of formal and informal services and benefits. The nursing profession, especially in the evolving independent role of the nurse practitioner, could also have a key role in the assessment process dependent on the location and operation of the assessment service at the local level.

The Council believes the various assessment instruments such as the questionnaires and schedules described earlier could expedite the work of the practitioner. These tools should never be seen as replacing the diagnostic and personal skills of a competent clinician. Whatever techniques or direct practitioners are utilized, access to multidisciplinary consultation would also be essential.

Plan of Care and Referral

Behind the concept of the Council that the assessment process and the development of the plan of care has intrinsic value whether or not that process has the power of certification for other formal help, is the belief that many older persons and the significant persons in their lives do have available certain resources which are not being fully utilized. The FCA is advancing the notion that a process which systematically identifies these formal and informal aids could be of great value to many older persons.

The Council believes there is value in skilled referral for help for which a frail older person might be eligible but which is not received for lack of skills in coping with the bureaucracy. This arbitary separation of assessment and case management in this FCA report again poses a problem. Many times effective referral can be a lengthy process and indeed an ongoing process for the frailest of the elderly who will need continuing assistance in coping with life's bureaucracies.

The FCA proposals for the frail elderly have been criticized for the possibility that the ideal plan of care which would be developed might recommend services which would not be available in a community or for which a particular frail person might not be eligible under current program restrictions. The Council agrees with these advocates for the elderly that there should be an array of services -- a continuum of care -- available in every community so that there would truly be alternatives in long-term care for older persons and the significant other persons in their lives. But until that day arrives, there is merit in identifying a means whereby available resources would be fully utilized and a process established for identifying unmet informal and formal aids in the community. Furthermore, national policies for non-institutional long-term care would have to be based on an assessment process. This approach puts in place the foundation for an incremental development of an overall policy on long-term care.

In the initial establishment of an assessment program, it would be important to build in mechanisms for quantifying and qualifying the needs of participants which cannot be met at the present time. These data should be fed into the community planning process for the aged and in such categorical areas as social services, physical and mental health, community development, health facility planning, etc. The assessment questionnaires could be valuable in providing information about unmet needs in a systematic way.

The program would have to operate in close cooperation with all community agencies responsible for planning and/or delivering health and social services both to the elderly and to the total population in need as well as to those government agencies administering benefit programs.

Administration and Financing

In trying to assure univeral availability of its proposed services, the Council considered the feasibility of direct administration by the Federal government. After all, the Federal government does guarantee the provision of certain services to certain favored groups like veterans usually by direct operation of hospitals and other services.

As reported, the Federal Council once considered the possibility of having the Social Security Administration, which touches the lives of the overwhelming majority of persons over the age of 60, administer its proposed services for the frail elderly. It decided against it for a number of reasons particularly the vastness of SSA's responsibilities. Furthermore, it felt that a program of services, as opposed to benefits, should be related as closely as possible to the family, the neighborhood, and community agencies and institutions.

Therefore, the Council has proposed that the core services for the frail elderly should be administered by a single State agency with Federal/State matching funding with flexible delivery at the community level.

The Council envisions the State agency as having overall responsibility for guaranteeing the quality and coverage of the program with State options as to where and how the service would be delivered at the community level. It could be a local counterpart of a State agency such as a county public health or social services office. It could be through a senior center, area agency on aging, long-term care center or a voluntary health or social service agency.

State government in this country has been providing certain aids for life management for its citizens for many years. However, a person's life has to become practically unmanageable before such aid as commitment by one unit of government, namely, the court, is made to another unit of government such as the mental hospital. At less restrictive levels and for less deviant behavior, the procedures of guardianship, conservatorship and other forms of surrogate management are frequently utilized by the courts.

Protective services are supposed to be available from public social service agencies for older persons in crisis because of the need for assistance in life management. Traditionally, the service has been of a short-term duration and offered primarily to recipients of public assistance.

What is different about the FCA proposals is the Council's advocacy of Federal government assurance of certain aids for life management before a crisis occurs and not because of some manifestation of a psychiatric disorder or poverty or inability to manage one's own resources.

The aid would be voluntarily accepted by the recipient, that is, not required as an exercise of the police powers of government. This does not mean that, in practice, this service might not be provided through the same agency charged with court-directed services for those in need of protection.

Provisions of the "significant other", so vital to the FCA plan, could be through a stimulation of the informal network of help, a cash payment, or direct provision of a helping person. Case management could be means-tested, fee-for-service, or a universal entitlement. Assessment would be offered as a "public social utility".

Alfred J. Kahn and Sheila Kamerman, writing in "Not for the Poor Alone" in 1975, describe these aids as constructive solutions to "normal" problems that arise out of societal change. "Indeed, the term 'problems' is probably inaccurate, since the programs involved represent appropriate, accepted responses to widely shared experience.

The need for assessment of the frail -- whether rich or poor -- has been evidenced. There is need for help of varying intensity for sorting out family feelings to finding the right nursing home when that is the overwhelming option for long-term care.

While the Council has accepted the concept of using advanced age for the "triggering" and automatic entitlement to receipt of the FCA proposed aids, there has always been some discomfort that this could discriminate against those below age 75, 80, or whatever age break would be agreed upon as having some validity for correlation with multiple impairments.

This is especially true for assessment procedures for non-aged persons with a chronically-disabling impairment or impairments. It is conceivable that the system could be made available and publicized as a voluntary aid for persons who:

- Had reached age 75 or
- Had one or several major functional dependencies or
- Asked for specific help for a strongly felt need.

Automatic access to assessment might gain legitimacy, acceptance and awareness if it were publicized as a normal process for persons of advanced age like a routine health check-up. Depending on whether assessment were lodged in a voluntary agency or a statutory agency with eligibility determination powers, the assessment program could be conceived by personnel working in the field of aging as a resource in some of the following events:

- Determination of need for home-delivered meals or any home-delivered service.
- Need to determine representative payee status for government benefit program.
- Determination of guardianship or conservatorship.
- Upon recovery from acute illness.
- At death of spouse or significant other person in one's life.

THE THIRD PART: CASE MANAGEMENT

Just as the Council was not completely satisfied with the nomenclature "frail elderly" neither was it happy with the term "case manager" for the person who would have the continuing relationship with the individual or "case". The Council sees the helping person as being a facilitator and a consultant for a person who still has the capability of managing many life decisions but needs some help in coping with life's bureaucracies because of the accumulation of the vicissitudes of increasing age not because of a single physical or mental trauma or a personal loss or role change.

The caseworker would have an ongoing but not necessarily intensive relationship with the older person once the initial assessment and plan of action had been developed. The role of the "significant other" person would be most important in this continuing respect and is described later.

When the most appropriate placement for an older person is in a health-dominated facility, the case manager could be involved with staff or the facility in arranging the move. Since institutionalization is not always permanent and to assure a personalization of care, the professional in the community might possibly maintain a relationship with the older patient to assure maintenance of community ties especially in cases of weak or non-existent family relationships.

It would be important that the dealings between and among the professionals be one of partnership and not of competition or neglect because of the presence of two sets of helping persons.

The frail elderly casework service would have the responsibility not only to identify the informal or formal services that exist in a community but to work with the older person and the significant person or persons in his or her life to assure that the services are received. The same approach would be utilized in assuring that the older person would receive all the government and private benefits such as Social Security, SSI and pensions to which he or she had an entitlement.

The aid being proposed by the Council would be offered voluntarily, that is not required as an exercise of the parens patriae responsibility of government. However, the service could well be provided through the same agency charged with court-directed services for those in need of protection. In fact, it may well be that services for the "mentally confused" older person might have to involve at least the statutory agency charged with protective services if not the court itself in order to fully protect the older person's civil rights.

Definition of Case Management

Since the central role of this professional person is that of a case administrator, it will require that he or she have a range of skills drawn from the fields of social work, public health, community organization, and, on occasion; must serve as advocate to assure that the interests of frail elderly and their families are maximized. The case manager must have expertise in local and State program offerings for the elderly, national benefits, and other program resources likely to be of direct value to aging persons and their families.

In essence, the caseworker serves a coordinating and linkage function, placing his or her skills and knowledge of the range of resources for the aging at the behest of the frail elderly and their families to enhance the quality of life for older people. Since it is the intention of this program to bring into play community-based, State and national programs likely to assist the older person's search for health and social sustenance, the caseworker will be expected to expose and help communities recognize deficiencies in current service provisions for the elderly. Information on service gaps are to be conveyed to the area's organized planning bodies, particularly the area agency on aging.

While the word "case" seems highly bureaucratic, it is the term of art for an individual unit of service and for an individual person or family. And "caseworker" refers to a professional person who deals with people on a one-to-one and one-by-one basis. This personalization of aid with hopefully the same helping person is essential to the FCA formulations. It is the bringing into the life of the frail person a "significant other" person who will work with the other significant persons in the life of the client where they are available. The caseworker is also to be responsible for making available when needed, assistance for simple personal care services on a sometimes daily but not 24-hour basis from another "significant other" helping person.

The relationship of this mode of practice to social work and the family is treated by Shanas and Sussman (1977):

> The roles of advocate, organizer, administrator and ombudsman are proposed as more salient roles for social workers dealing with the elderly than the provision of emotional and other affective supports, which can be most effectively provided by members of a family and kin networks and, if not by them, by less professional persons.

Shanas and Sussman call for greater parity in the relationship between the client and the professional with bureaucracies serving as consultants to older persons and their families, "The task is how to more effectively involve family and kin network in long-term care of the elderly and to do this without using the power of law and without destroying the internal dynamics of the particular family unit."

In discussing the need for personal care service by the elderly and others requiring long-term caretaking attention by other adults, Morris and Anderson (1975) identify social work as bringing a professional and ideological approach, an approach revolving around the concept of psycho-social intervention.

Morris (1977) advances the premise that technological advances which now enable numbers of young persons with various congenital and disease conditions and victims of accidents to survive well into adulthood with their handicaps as well as increases in the numbers of old, frail persons means that society must be concerned about long-term "care", as much as "cure" and prevention of disabling conditions. Morris identifies the emergence of the case-management concept as a starting point towards a caretaking approach to the needs of these chronically impaired populations.

> Case managers ...are supposed to handle all aspects of serving human needs, including assessment, counseling, and caretaking. To date, although they have been given this charge, case managers have not been given the authority or means truly to manage services and cases. Most of their work is still the voluntary coordination of the work of others. The next logical step would be to invest them with the authority and responsibility for caretaking functions out of which continuity of care could flow.

Morris goes on to describe, as a model of the concept of case management and continuity of care, the HEW demonstration projects on Service Integration Targets of Opportunity. These coordinate fragmented services by co-location of independent agency offices at a common site, by formal referral contracts, by wider information systems, and by active administrative merger. Morris sees the social work profession as being responsible for the creation and management of social environments. "In these social environments, psychological and other clinical treatment services would be given, but the profession would emphasize management of the social environment."

Wasser (1974) describes the casework practice in the Benjamin Rose Institute protective services study as highly eclectic. Emphasis was placed on use of relationship and on psychodynamic understanding of client personality. Attention was given to intellectual processes, and led to viewing behavior as connected with functioning, organicity, and health. "The case management component became essential because of the range of resources used from within the agency and outside, and the necessity for directional control and coordination in the case situation."

Social work's unique contribution is further delineated in a policy statement adopted by the National Association of Social Workers in 1976:

> The case-by-case intervention in social circumstances and conditions as the means of alleviating problems and promoting positive functioning in individuals and families is an early hallmark of the profession which must be recognized as a key service to the frailest and oldest of the elderly. Social diagnosis and social treatment are major missing elements in current national

> policy formulations be they characterized as improving nursing home care or alternatives to institutionalization or developing coordinated, comprehensive community service system. These unique social work skills are essential to the development of a system of services for those persons with chronically disabling conditions who require ongoing personal care services... Knowledge of the community and its resources makes the social work profession particularly suited to assisting the elderly and their advocates in dealing with and understanding the complexities of Society.

Keith-Lucas (1973) describes some basic philosophies of public social service which are useful in understanding the nature of the social casework advocated by the Federal Council.

> Therapeutic -- People who need services, including the vast majority of the poor, have something wrong with themselves or their situation which needs to be diagnosed by a social scientist, to be followed by some kind of treatment. It was the basis of the 1962 Public Welfare amendments to the Social Security Act which promised to solve major social problems through changing the individual's power to cope with life.
>
> Social utilities -- This is the "warehouse" model with a philosophy that social services are things which people may want and are entitled to get if they choose. These are looked on as "social utilities", much in the same way as fire or police protection. People order, rather than apply for them, as from a store. Since those who provide the service might be niggardly or prejudiced, the consumers of service would have access to an expediter or advocate -- generally of their own social class, ethnic background and level of education -- who could demand that service be given promptly and efficiently when ordered.

These two philosophies are dismissed by Keith-Lucas on the premise that the first is undemocratic and depends on a trained elite of persons infected with social science concepts. The second oversimplifies. "Social services are not as a whole, discrete packages -- things one can order and apply to oneself like a poultice. Some are comparatively simple, but many are quite complex interdependent processes that may need a great deal of exploring before one can be sure what suits one's situation best... Some services, such as supportive visiting, badly needed by many old people, are hard to put in a form in which they would be likely to be asked for directly."

Keith-Lucas advocates a philosophy of public social service, based on Judeo-Christian philosophy, which accepts the fact that people, although fallible, are generally capable of managing their own affairs. "It holds that, in the extremely complex and rapidly changing society of today, people frequently need help in planning from various kinds of specialists... It is a philosophy neither of elitism or class struggle but of man's essential interdependence."

The basic service in the Keith-Lucas philosophy is "co-planning". "It may stand alone as a service, or it may be an integral part of any other service to which it has led." He sees it as voluntary even in those cases where law has intervened. In these instances, co-planning is offered as an alternative to legal sanctions, where what needs to be done is often for the client to come to terms with the reality of this intervention.

Keith-Lucas describes the skills which are needed in giving both a basic co-planning service and the more specialized services that accompany it. The worker must learn the basic helping process and the development of his or her ability to convey reality, empathy and support to other people; secondly have a good understanding of the structure, relationships and effects inherent in some services. Indigenous personnel are to be used in such a system, not only in many direct services such as supportive visiting but also as two-way interpreters of what is available and what ought to be made available. He concludes:

> Advice relating to ethnic patterns would be available, but indigenous workers, would I hope, avoid the adversary implications that are sometimes assigned in a warehouse system. To start with, the belief that services will only be given grudgingly or with prejudice is to deny the value of services of any kind. Thus one can incorporate many of the good elements of the warehouse concept, including its voluntarism, its emphasis on rights, its view of services as a public utility.

Illustrations of Case Management

The following illustrations of case management practice in a variety of settings is not meant to be definitive. These particular undertakings contain some of the elements of the kind of program envisioned by the Federal Council.

OARS Clinic - Duke University

As part of its scientific research program, the Center for the Study of Aging and Human Development at Duke University operates a clinical program for older residents of Durham County, North Carolina, as a service to the community and to test appropriate research projects. Evaluation is offered to "those encountering difficulty in adapting to old age". Following systematic evaluation, a service plan is designed for those persons thought to require services. OARS clinic personnel subsequently provide certain kinds of services, primarily of a counseling nature, directly to such persons and their families while arranging for and coordinating additional services available elsewhere in the community but not in the OARS clinic itself.

The OARS clinical program consists of the following elements:

- Administration of the OARS "Multidimensional Functional Assessment" questionnaire by a trained worker (interviewer). (See pp. 125,126)
- Interview by a clinician, usually a social worker or psychiatrist, for additional information.
- Determination by a clinician, upon completion of evaluation process, of the following:
    1. Level of functioning in social, economic, mental health, physical health, self-care capacity
    2. Specific services needed
    3. Optimal setting in which these services could be provided

In describing the operation of the OARS clinic, Pfeiffer says that the most important clinical service offered is not a specific intervention but rather the coordination effort of all the services required by an individual while continuing contact is maintained with the individual. "In fact, in terms of our list of services we have placed this at the highest level, even though the idea of coordination of services before any services have been named may superfically seem to be absurd... The second most important service offered...is counseling with family members rather than counseling of the older person himself or herself. It has become clear that unless the family understands and accepts recommendations and information regarding the older impaired person, no successful treatment program is likely to remain stable."

Chronic Illness Center - Ohio

This Cleveland program (Luppens, 1976) was initially funded by a combination of Federal monies from the Ohio Commission on Aging and State mental health funds administered by the Cuyahoga County Mental Health and Retardation Board. Service was offered for the first time in November 1969. When the Federal funding terminated two years later, the Protective Services for Older Persons demonstration program was merged with the Chronic Illness Center, a community-based unit of the Cuyahoga County hospital system which offers a multi-disciplinary approach to services for the aged and chronically ill.

Currently, the protective services program remains a vital part of the Center's total services and is funded by State mental health monies which are matched by county funds. The mental health contract provides a channel for some additional Title XX money.

A multi-disciplinary approach has been utilized since the program was established. Social work and nursing are the key disciplines with back-up from medicine, psychiatry and law. Staff are organized into teams consisting of a coordinator, two caseworkers, a geriatric outreach worker, a nurse and a secretary. The coordinators are experienced masters-level social workers who can assume the added responsibility of supervision of the caseworkers and geriatric staff.

The role of the geriatric worker has evolved from performing specifically assigned tasks, like accompanying an older person to a clinic, to being utilized more and more as an extension of the caseworker. This paraprofessional supplements in providing supportive attention and performs personal services such as shopping and seeing that bills are paid.

Fiscal data for 1975 provided by the Cleveland program project an annual cost of $1000 per person for case management services.

Protective Services for Adults, New York State

Upon learning of the Federal Council's activities on the frail elderly, Robert O'Connell, Acting Director of the Bureau of Community Services of the New York State Department of Social Services, wrote expressing concern about the implications for service delivery of the FCA proposals. Material was sent describing the activities of the State in implementing Title XX mandated protective services for adults. In addition to Title XX, the program also operates under State statutes which establish responsibilities of local commissioners of social services relating to mentally ill persons, including court proceedings regarding incompetency and conservatorship of property.

The State's protective services program recognizes the particular need for these services by the increasing number of mentally impaired adults returning to and/or remaining in local communities. The need for specialized services to individuals being released from mental hygiene facilities was emphasized by passage of State legislation in 1974 mandating cooperation between social services and mental hygiene officials in helping those patients toward self-support and self-care.

New York defines protective services as -- a system of care (for adults) which includes the availability of a constellation of services brought to bear individually or in concert upon a problem situation of an adult requiring a planned approach of intervention. As a preventive, supportive and surrogate service, it is aimed at maintaining individuals in the community as long as feasible rather than institutionalizing them, though in some cases, the latter may be necessary. More specifically, it can be stated that a protective service system aims at the prevention, reduction or elimination of neglect, exploitation or crisis breakdown through the provision of services appropriate to the individual's needs which will strengthen his capacity to function and maximize his ability at self-direction.

Case management/counseling is the core of an effective protective service program. Local protective service staff must have knowledge and skill to assess and evaluate, to make decisions, to enlist other medical, psychiatric and legal help as necessary in evaluation and treatment and to coordinate those services which should alleviate the individual's plight.

In his correspondence with the Council, the New York State official asks if the frail elderly whom the Council addressed would meet their defined criteria for protection or if this population is being viewed in the broader context of prevention. He goes on to say that rather than isolate the frail elderly over age 75 as a separate client category, it would be well to consider that 20% of this population is potentially endangered and that the money and effort should be expended in the existing service programs to find these people and provide preventive as well as protective services.

He writes: "In the present system, at least in New York State, because of dearth of funds, very little can be provided preventively and situations must reach crisis or near crisis proportions before they come to our attention for protective services. Establishing a separate delivery system will only fragment further the present system, build local bureaucracy and possibly place the diverse systems in competition. An integrated approach with incentive funding would appear a better approach."

Relationship Between FCA Case Management Services and Protective Services

The question raised by New York State about the basic differences between the case management being advanced by the Federal Council and protective services as envisioned by Title XX is a valid one.

In examining the literature of protective services and in discussions with practitioners and academicians at the national and local level who had been and were involved in protective services, one thing is clear. The Title XX law and regulations might have certain definitions of protective services but what is being practiced is different in every State. No one has the kind of data base upon which to provide a national insight.

So the questions from New York will be answered from the perspective and perception of how protective services operate in that State. It would seem that the Federal Council did intend for its services to be of a preventive nature and its "triggering" being the attainment of a certain advanced age. This contrasts with protective services being available upon manifestation of an inability to manage one's own resources or to protect oneself from neglect, exploitation or hazardous situations without assistance from others.

Whether the provision of the less authoritarian service envisioned by the Council requires a separate delivery system is less clear. This can only be answered as more data are obtained about the evolving nature of protective services practice.

Currently, there would seem to be two divergent trends regarding the use of authority in the protective services relationship. On the one hand, there is advocacy for the greater involvement of the courts to assure the rights of older mentally-impaired persons to the least restrictive modality of care. Other workers in the field state that in dealing with frail adults in need of protection, there is little need of legal intervention when the helping relationship is skilled and sensitive to the capacities of the client for self-determination and self-direction.

The Federal Council's limiting its service proposals to case assessment and management might also be considered as another difference with the definition of protective services as including and requiring a "cluster of services" such as homemakers, day care, home-delivered meals and transportation. Also, the FCA envisions the need for long-term case management of varying intensity while protective services as practiced currently would seem to be of limited duration and geared to crisis situations.

Lola Hobbs does not agree on the need for a cluster of services as intrinsic to the basic nature of these services. Writing in Public Welfare in the Summer 1976 issues, she says:

> The definition of protective services is crucial to the design and implementation of programs. While earlier definitions tied protective services to a narrow legalistic approach, later developments removed all boundaries and, in effect, left programs with very little structure to guide program planning.

She believes that the primary, essential objective to be achieved by protective services is to enable the partially or totally immobilized client to control or contain behaviors or circumstances which are endangering the client or other members of the community. "The fundamental element necessary to achieve that objective is authoritative intervention in the decision-making process itself. The critical program elements are a social worker and a social services agency, both of which are willing to accept the responsibility and risk of making decisions on behalf of another. No auxiliary services as such are intrinsic to a protective services program."

In advancing the social casework model of the Federal Council, it is obvious and important that its relationship to the psycho-social nature of protective services and to psychiatric services, which might be available from a community mental health center, will need to be considered.

Projecting Costs and Caseloads

For assistance in weighing the feasibility of the FCA proposals, Dr. William Bell, Consultant to the Council for the frail elderly project, developed the following estimates on possible costs and caseloads for the case management service. However, it should be noted that these computations are based on the service being separate and new rather than an expansion or variation of one or several existing programs.

Table 1

Current Potential Demand by Frail Elderly For Projected Program

Category	Size of Estimated Demand
Estimate 1	773,500
Estimate 2	853,000
Estimate 3	1.7 million

Estimate 1 is derived from Nagi (1975), who indicates 9.1% of individuals aged 75 years and over require personal care assistance, that is, help with normal activities of daily living such as getting dressed, feeding, personal hygiene and the like. Estimate 2 is a crude adaptation from data from the National Center for Health Statistics on chronic conditions among the elderly. Estimate 3 is from Nagi as well, but refers to 19.9% of the group 75 plus in the United States with severe limitations on physical performance.

It should be noted these estimates cover eligibles to the program not necessarily actual client numbers. From the perspective of the frail consumer the program is voluntary, an option he can exercise or reject. It can be assumed an unknown proportion will opt not to avail themselves of the program.

Faced with a dearth of hard information on estimating market demand for the Council's proposed service, the figure of $1000 per client per year is used as a crude average cost per client. On that basis, and using the three estimates of size of the target population in Table 1 as the potential upper limits of the program, estimated costs are cited in Table 2, below.

Table 2

Estimated Costs of Proposed Program

Category	Financial Outlay
Estimate 1	$773.5 million
Estimate 2	$853.0 million
Estimate 3	$1.7 billion

It should be added that the projected costs for each level are based on the caseworker carrying an average case load of 100 clients per year at all times. The $1000 per client is further assumed to be sufficient to carry the budgetary demands of salaries and fringe benefits, training, administrative supervision and related support, office expenses, equipment, travel and conferences.

In a period when there is a growing consensus that some Federal revenues are probably needed to maintain the soundness of our present social insurance programs, and will probably be needed in any incoming National Health Insurance plan, a program with strong social merits but with firm service limits, such as the one proposed in this report by the Federal Council, may just as well be completely financed from general revenues from the start.

EPILOGUE

(Comments offered by Monsignor Charles J. Fahey, former chairperson of the Council's Task Force on the Frail Elderly).

From the outset this project has been designed to engage leadership persons from all sections of the country towards the evolution of an enlightened public stance in regard to those elderly who are most vulnerable.

Many questions have not been satisfactorily answered, though approaches have been forwarded to address them; for example, whatever has been said of the frail old can be said of virtually all those who are vulnerable within our society. Since the Federal Council on Aging has jurisdiction in regard to the elderly, our deliberations have concerned them primarily; however, the Council cannot help but be cognizant of frail persons who are not old - their plight is similar to that of many of the "frail elderly". An important policy issue is the development of an age-related service as opposed to one that would provide social support systems for all, regardless of age, who are similary at risk.

From the outset, the establishment of a presumptive eligibility reaching all persons over a certain age (over seventy-five) was perceived as a politically viable way to begin a system which would have some definition to it and would reach those who are most in need. It should be clear from the various background material, as well as from the policy actions taken by the Council, that there is deep concern for all frail elderly. Further attention must be given to a technique to establish eligibility in a simplified manner, so that such service or services will be available to all older persons who need it.

The Council has been troubled by the status of those persons in our society belonging to various sub-groups whose longevity is different from the over-all population.

The Federal Council on Aging is engaged in several efforts to understand their needs. Is the onset of fraility different by reason of race? Does equity require different age thresholds of eligibility for various groups within society? Were a technique utilizing need, in addition to age, developed, the Council has data from practice as well as from research which could be the basis for answering such questions.

This Staff Report also serves to highlight for the Federal Council on Aging various options which are available to it in regard to future activity. The Council is weighing its priorities in the light of various new mandates given it under the re-authorized "Older American's Act", as well as various societal happenings.

Of particular importance is a decision on whether or not the Federal Council will forward the Frail Elderly Concepts in the form of a specific legislative proposal, or whether it will hold all legislative initiatives up against the criteria or principles inherent in the concepts of the support system for the frail elderly.

If the former course is chosen, then additional strategy steps must be developed concerning the proper vehicle for legislative consideration: i.e. through initiation of the Administration or through some particular sponsor in the House or Senate. If the latter strategy is adopted, then legislation regulation which impacts upon the frail elderly must be identified, so that they can be judged in regard to the frail elderly principles and specific suggestions may be made so they may contribute to a societal support system for the frail elderly.

The Federal Council may choose a combined strategy, which both forwards a specific piece of legislation for educative purposes as well as for action and at the same time views all initiatives in the administrative and legislative side of government which will affect the frail elderly.

Even as the Federal Council has undertaken this study and continued leadership in it, it is gratifying to note that both in the governmental and in the voluntary sector there are serious discussions and deliberations taking place generally around the challenge of the frail elderly, as well as in regard to the Federal Council on Aging concepts of how to deal with it. The development of a national debate is a hopeful one, not only in regard to the important issue at stake, but also in regard to the leadership role which the Federal Council has exercised. It gives further promise of a continuing role of issue identification and clarification which the Federal Council can exercise in a variety of other areas.

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APPENDIX A

The following outline was developed by FCA's Task Force on the Frail Elderly and widely circulated as a systematic means of obtaining information.

1. POPULATION AT RISK

Can we achieve a public policy based on the hypothesis that there are so many people so much at risk that at some certain point the program of care gets "turned on"?

Are any one or several of the following the indicator of the population at risk?

age, debility, income, race, sex, marital status, living arrangement, milieu, geography.

2. SCOPE OF SERVICES

What is the goal and intent of each or all services?

Can a basic set of services be determined?

Can there be a place where people can develop whatever is needed and one's entitlement is access to that place that does whatever you need rather than to an individual service (Morris personal services concept)?

Is intensity and level of the service a criteria?

Is geography a factor in delivery and availability?

Should services be age-only or multi-generational or both?

Are any one or several of the following the appropriate service package:

social casework, counseling, coordination, advocacy, brokering, ombudsmanship and "benign oversight"

assessment: social, medical, etc.

reassessment

prescription, recommendation, plan

transportation

nutrition

maintenance: physical environment, personal support

3. SYSTEM OF SERVICES

What system should be developed to deliver the services?

How are roles of family and friends enhanced?

Should it be age oriented or multi-generational?

Should it be centralized or decentralized?

Should it be governmental - Federal, State, local?

Should it be regional or local jurisdiction

Should it be private - voluntary or proprietary?

Should it combine government and the private sectors?

Should it be categorical or generic?

Are one or several of the following elements of a system of services:

a. planning - coordination

b. assuring service

c. delivery

d. monitoring

Should the system be built on the existing health care system (Medi[illegible]care - Medicaid) or the multi-generational social services (Title XX) or the aged-only services (Older Americans Act) or a new system?

How complex and broad can a system be and still work?

4. MANPOWER NEEDS

Are new types of personnel needed to operate services for the frail elderly? How defined?

What numbers of personnel will be required?

What kind of short- and long-range training will be needed?

5. SPONSORSHIP

Should the auspices or sponsorship of the system be any or several of the following:

a. public or private

b. proprietary or non-profit

c. health or social services system

d. national, state, sub-state, local

What should be the relationship between and among existing social and health planning agencies?

What should be the role of the individual citizen including the consumer, client, patient?

What are roles of family, relatives, friends?

6. BENEFIT - ENTITLEMENT

Should it be a categorically funded, generic program for a target group?

Should it be an entitlement tied to an individual?

Should it be an insurance program?

Should the individual participate in cost-sharing through a deductible, co-insurance or a means test?

7. FUNDING - REIMBURSEMENT

Should there be provision for capital funding and start-up costs?

Should the services be financed through any or several of the following measures:

general tax revenues

dedicated tax - trust fund - employer contribution

voluntary - mandatory

participation by consumer in premium payment

use of private insurance carrier

Federal - State - local match

voluntary funding

vendor - voucher

direct payment to consumer

8. PHILOSOPHICAL RATIONALE

What services should the frail elderly have because they are citizens and a population at risk? Are these services a right?

Can these basic assumptions be made: that these are services which cannot be cashed out and that an income floor is guaranteed?

How can freedom of choice and self-determination be assured while at the same time providing needed protection?

What should be the nature of filial responsibility?

How can family involvement be enhanced?

How can universality and equal access be assured?

How can there be sensitivity to racial minority needs?

Are there special problems for frail older women?

How can the role and status of the frail elderly in society be maximized and enhanced regardless of their level of productivity?

Should need be the only criterion for service? Should age be the only criterion for service?

How is quality of services monitored?

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APPENDIX B

The following hypotheses and questions were used to secure data and arrive at Council decisions.

A. FRAIL POPULATION

There are many persons within the aging population who because of an accumulation of various continuing problems require the assistance of a significant person from time to time to aid in coping with certain daily life activities.

1. What data exist to show the correlation between frailty and advanced age?
2. To what extent do older people experience "plateaus" of frailty, and to what extent is there a rather steady increment of attributes of functional frailty?
3. What are the major symptoms of increasing frailty, at what age and in what sequence do they typically appear?
4. What are the major differences in the nature of the frailty between the sexes and among racial and ethnic groups?
5. What data are available on the number of the frail elderly in the USA? Are data available on their geographic location?
6. What is the extent and nature of assistance provided by family and friends to older persons?
7. What formal and informal benefits and services are available to the majority of older persons?

B. GOVERNMENT ASSISTANCE

Where there is limited or no continuing availablility of a significant person, certain aids for life management should be assured by government if agreed to by the frail person.

1. Should there be incentives to enhance the roles of families and friends? If so, what should these be?

2. Would a government sponsored program strengthen or weaken family responsibility for the frail elderly?

3. What is the nature of existing medical, psychiatric, social, legal and housing services for the frail elderly in a community? Are there substantial differences in rural and urban areas?

4. When older persons have several problems of a continuing nature, how are services delivered in a coordinated manner?

5. How can there be assurance that the least restrictive services and care are provided consistent with the person's needs and civil liberties?

C. CORE SERVICES

The Federal Council on Aging proposes that this assistance be available on a universal basis as an entitlement and be primarily of a social support nature consisting of the following services: case assessment, plan of care and case management.

1. Is it feasible to provide these services as a universal entitlement? What would the costs be? How many people would need the services?

2. What elements should be included in the assessment and how extensive should it be?

3. Should the assessment primarily be a case study by a professional?

4. Can an assessment tool be used? Should it be administered by a professional or a para-professional?

5. Should the person who does the assessment also be the case manager?

6. Are these skills primarily in nursing, social work or other disciplines?

7. What should be the role of consulting professionals as back-up to the FCA set of services?

8. Can national standards be developed for the FCA set of services?

9. Should the FCA set of services be available to family and friends of the frail older person who cannot or does not wish to use them?

10. How does this FCA set of services differ from current protective social service?

11. How do the FCA set of services relate to such legal procedures as commitment, conservatorship and guardian ship?

12. Could these services be a gateway to eligibility for the following federally-assisted programs:

    Medicaid
    Food Stamps
    Supplemental Security Income
    Federally Assisted Housing
    Designation of Representatives Payee for SSI and OASI
    Nursing Home Placement
    Community Mental Health Centers
    Veterans Administration

D. ELIGIBILITY

The core services should be available on the basis of presumptive eligibility, determined on the basis of attaining a certain age; e.g. 75. Persons below that defined age with need for these services should have access through some form of functional assessment.

1. Do the administrative benefits of presumptive eligibility outweigh the burdens of individual determinations of eligibility?
2. If age 75 is not acceptable as a determinant of presumptive eligibility, then which functional disabilities of elderly below age 75 are sufficiently widespread and acceptable to cleanly define those eligible for the program?
3. How are differing longevity rates among races and between the sexes be taken into account?
4. Since older women constitute the majority of the frail elderly, what preventive actions are recommended to diminish frailty among females while they are still in the labor force?
5. Should this same set of services be available to nonaged vulnerable groups in the population who have chronic disabilities: i.e., developmentally disabled, mentally retarded?

E. ADMINISTRATION

The core services should be administered by a single state agency with Federal/State matching funding with flexible delivery at the community level.

1. Could any or all of the following be utilized for delivery of the set of service at the community level:

   a. community counterparts of State agencies; i.e., local welfare offices etc.
   b. multi-purpose senior center
   c. area agency on aging
   d. long term care center (Conable)
   e. voluntary health and social services agencies

2. Should this agency provide the service itself; contract it out; or a combination thereof?
3. What should the Federal match be?

F. SIGNIFICANT PERSON

When a significant person is not available or has not been identified through the case assessment, priority in developing the plan of care should be given to the provision of such a person.

1. Is there a role for volunteers as the significant person? If so, how would volunteers be recruited, trained, placed and supervised?
2. Should the older person be involved in the selection and placement of the significant person? If so, how?
3. If the significant person cannot be arranged for through family and/or informal supports, could this person be provided through a cash supplement to SSI?
4. What protective measures, if any, are indicated to assure that a frail elderly person receives adequate assistance from the significant person?
5. Should special efforts be made to include older persons as "significant persons"?

G. REFERRAL

Any other services identified as being needed or desired are to be obtained from informal or formal services and benefits available to older persons.

1. How does the FCA set of services relate to any other benefits and services usually found at the local level:

   a. Community Services Administration
   b. Veterans Administration
   c. Services in the Older Americans Act
   d. Senior Centers
   e. Title XX
   f. Medicaid
   g. Food Stamps
   h. Supplemental Security Income
   i. Community Mental Health Centers
   j. Homemaker-Home Health Aide Services
   k. Health Care Services
   l. Long Term Care Facilities
   m. Voluntary Health and Social Service Agencies and Institutions

2. How can the program for the frail elderly be implemented in communities where a range of supplementary services is not available?

H. UNMET NEEDS

A mechanism should be developed for providing data about the unmet needs of the frail elderly to community planning agencies and leadership/advocacy groups.

1. How can the frail elderly "system of services" provide in-put to such State and sub-State advocacy and planning activities as those carried out by the area agency on aging, public social services, United Way, senior membership groups, health systems agencies, etc?

2. How can informal services be expanded to meet the needs of the frail elderly, particularly in areas where few, if any, formal services are available?

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